

The Effects of Cancer on Romantic and Sexual Relationships for Young People Entering Adulthood

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ABSTRACT

In the UK, approximately 2600 adolescents and young adults (AYAs) aged 15-29 are diagnosed with cancer each year (Cancer Research UK, 2018), and improved prognosis rates has led to more focus on 'survivorship'. Current literature suggests that AYAs' romantic relationships are a significant source of support during cancer, but that dealing with the disease can also exacerbate conflict. Young people may re-evaluate their life and change their priorities, which can either hasten the end of poor quality relationships or bring couples closer together.

Drawing on recommendations in the literature, this study focused on a specific period during the AYA years (young people in their 20s), using a UK population. Underpinned by a critical realist epistemology and using a qualitative methodology, it used semi-structured interviews to gather the experiences of 6 women and 5 men aged between 20 and 28, with an average of 3 years since diagnosis. All had a range of experiences in terms of relationship 'status' during their experience of cancer.

Using an inductive thematic analysis, four interconnected themes were constructed from the data: 'Construction of romantic relationships in context', 'challenge and change', 'managing changing perceptions' and 'different selves and new perspectives'. Similarly to previous research, the findings highlight the particular importance of romantic relationships for young people, and the attention they deserve for researchers concerned with AYA cancer survivorship. Importantly, romantic relationships appear to be intrinsically connected with development of identity, which can be challenged and changed by the cancer experience. If navigated well, this change can be for the better, leading to more fulfilling relationships in the future.

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1. INTRODUCTION

In the UK, approximately 2600 adolescents and young adults (AYAs) aged 15-29 are diagnosed with cancer each year, representing approximately 1% of the total cancer population (Cancer Research UK, 2018). In the US, 70,000 AYAs aged 15-39 are diagnosed annually (National Cancer Institute, 2018), and incidence rates across Europe show a similar pattern (Stiller et al., 2006). Worldwide, young adults aged between 20 and 39 account for nearly a million new cases of cancer per year; 43 in every 100,000, or just under 0.5% of the total cancer population (Fidler et al., 2017). Over half of all new AYA cases in the UK are diagnosed in people aged between 20 and 24 years (Cancer Research UK, 2018).

1.1 Common Cancers and Prognosis Rates in AYAs

In simple terms, cancer is a collection of related diseases where abnormal cells divide in an uncontrolled way, spreading to other tissues in the body (National Cancer Institute, 2018). There is a type of cancer for every cell; each with its own trajectory, symptoms, mortality rates and type of treatment. Although cancers are most commonly found in middle or older adulthood, there are a significant group of diseases whose peak occurrence is in adolescence and young adulthood: Lymphomas, carcinomas and germ cell tumours account for almost a 3rd of cases in AYAs (Cancer Research UK, 2013). Although relatively rare, incidence of cancer is more common in AYAs than in childhood, and is increasing (Croucher, Whelan, Møller, & Davies, 2009). AYAs are approximately 2 and a half times more likely to develop cancer than children under 15 years (Bleyer, Albritton, Ries, & Barr, 2007), and since the 1990s, incidence rates of AYA cancer have increased by 33%, the highest rate of all age groups (Cancer Research UK, 2018). Globally, there are similar reports (Adamson et al., 2007). Although it's not known why this is the case, improved detection rates are likely to play a significant part.

The type of cancers most commonly affecting this group are not only distinct from those found in childhood and older adulthood, but generally less well-

known. A small number present with cancers usually seen in adults or children, but the biology of a cancer in an AYA may be very different from that of the same disease in an adult or a child (Barr, 1999; Birch et al., 2002). Most of the common cancers have a relatively good prognosis, with over 80% of young people expected to survive for 5 years or more after diagnosis in developed Western areas (Cancer Research UK, 2018; National Cancer Institute, 2018). But surviving cancer puts young people at risk of a wide range of health problems: 96% of survivors had a chronic health condition that was severe or disabling, life threatening or fatal by the age of 50 (Bhakta et al., 2016). Nor are they likely to remain in survivorship for the rest of their life. Due to the longer life expectancy of the age group, intensity of the initial treatment, and genetic factors, the risk of developing a new type of cancer is higher than it would be for older adults (Soliman & Agresta, 2008).

1.2 A Distinct Group

Researchers have argued that AYAs are a distinct subgroup within oncology requiring specialist care (D'Agostino, Penney, & Zebrack, 2011). Not only does the disease biology and treatment differ from that of children and older adults (Barr, 2007; Ramphal, Meyer, Schacter, Rogers, & Pinkerton, 2011), but its challenges coincide with a particularly sensitive stage in biopsychosocial development (Docherty, Kayle, Maslow, & Santacroce, 2015).

In the last 15 years, a growing commitment to improving the quality of care for AYAs has led to more research into the impact of cancer on young people's psychosocial development. However, there is still relatively little attention paid to AYA cancer compared to that of children and adults, despite evidence that incidence of cancer in AYAs is growing at a faster rate than amongst children (Bleyer et al., 2007), and concerns that improvements in survivorship rates have not increased at the same rate as children and older adults over the last 25 years (Croucher et al., 2009; Stiller et al., 2006).

1.3. Changing Priorities: Cancer Survivorship and Quality of Life

Over the last 50 years, societal discourses around cancer have shifted, largely thanks to medical advances in treatment. The increased likelihood of living beyond cancer has led to increased discussion about cancer survivorship in academia (e.g. Journal of Cancer Survivorship) and political health initiatives are increasingly focused on issues of survivorship, increasing funding and research to the area (e.g. National Cancer Survivorship Initiative). Quality of life in survivorship, including support for families and other networks around the cancer survivor, is recognised as a key priority for health commissioners and health care professionals of the future (NHS England, 2016).

Interest in issues of survivorship for AYAs is particularly salient, as they spend far greater portions of their lives with the physical and psychological consequences of their disease. Long term physical changes have emotional and psychological effects (e.g. memories and meanings of scars, worry about cancer returning) for the rest of a young person's life, and cancer has the potential to affect life choices and outcomes much more significantly than for older adults who have already lived the majority of their lives.

Despite these needs, the population remains understudied (Kent et al., 2012). Young people report a lack of resources and of being ill-prepared for the challenges of survivorship. These include physical symptoms that continue to pervade their lives, and psychological adjustment to a new identity: 'Being neither sick nor healthy' (Hauken, Larsen, & Holsen, 2013; Wolff, 2007).

1.3.1 Defining Survivorship

Definitions of survivorship vary and are contested (Surbone, Annunziata, Santoro, Tirelli, & Tralongo, 2013). In the UK, a cancer survivor is defined as an individual who has completed initial treatment, regardless of their prognosis (Department of Health, 2010). Mullan (1985) proposed three stages: The 'acute' stage as the initial stages of diagnosis through to the end of treatment, the 'extended' stage as the post-treatment period of remission consisting of frequent follow-up hospital visits, and 'permanent' survival stage as gradually evolving from a lengthy period of being cancer free. Long-term survival has

also been defined as 4-5 years after the first diagnosis (Aziz, 2007) or treatment completion (Grinyer, 2009).

1.3.2. Psychosocial Issues for AYAs in Survivorship

For people of all ages, life after cancer includes emotional, cognitive, social, sexual and spiritual changes which are often unforeseen during the turbulent diagnostic and treatment stages. These vary considerably for each person and are determined by the type of cancer and by other social and personal circumstances and characteristics.

Drawing on evolutionary psychology and cognitive theory, Brennan (2001) put forward the 'Social-Cognitive Transition Model', to map the psychological processes involved with the cancer journey, and add to our understanding of why people appear to cope differently from others. Cognitive theory purports that people acquire mental models of the world through implicit learning throughout their lives, and these mental models enable us to anticipate and negotiate each moment as part of a relatively continuous and coherent narrative. Emotions occur when events challenge the mental models and assumptions that we rely upon for coherence, predictability, and control (Rimé, 2009). Therefore, when faced with events that violate our expectations and assumptions, we require a period of psychological and social adjustment, as our mental models (and the mental models of those around us), accommodate and assimilate what has happened, and we can make adjustments to our models for making sense of our experiences in the world. The period of adjustment consists of several simultaneous and connected processes that occur over time as people manage to learn from and integrate changes arising from the altered reality of their lives.

The adjustment to cancer is thought to be particularly challenging for AYAs (Grinyer, 2009), who suffer greater psychological distress and have poorer psychosocial outcomes than children or older adults (Pearce, 2009; Roberts, Piper, Denny, & Cuddeback, 1997). At a life stage characterised by

considerable turbulence and flux, cancer presents an additional challenge that may severely interrupt the normal¹ developmental trajectory.

Reviews of the literature report on the widespread range of issues facing AYAs in survivorship related to physical and cognitive changes, restricted activities, change in relationships with others, compromised fertility, emotions, body image and spirituality/outlook on life (Sodergren et al., 2017; Warner et al., 2016). AYAs often experience particular distress around body image and physical changes, leading to feelings of unattractiveness and low self-esteem. Many will experience problems with sexual function or compromised fertility, and some with difficulties developing and/or maintaining intimate relationships. Changes to peer and social relationships can be particularly difficult, as can loss of independence and disruption to work and/or education (Abrams, Hazen, & Penson, 2007; Sodergren et al., 2017; Warner et al., 2016; Zebrack & Isaacson, 2012).

Although long term survivorship outcomes are still unclear, a few longitudinal studies suggest that negative effects (e.g. anxiety and body image disturbance) can continue for many years after the initial treatment phase, and often in a non-linear and unpredictable way (Abrams et al., 2007; Grinyer, 2007; Lehmann et al., 2016; Pendley, Dahlquist, & Dreyer, 1997).

All these areas are affected by the physical, cognitive and psychosocial and developmental stage of the individual young person, as well as numerous other variables in interaction with each other. Piaget (1970) suggested that the 'formal operation' stage begins around the age of 12 and continues to develop until aged 30+. The AYA with cancer is therefore still developing their full capacity for abstract thought, deductive reasoning and conceptual thinking. Theoretically, they have the ability understand the full ramifications of cancer in a way that a child cannot, but they also lack the emotional maturity and experience to cope in the way of an older adult (Eiser, 1996).

¹ The term 'normal' reflects the source literature's terminology, but it is recognized that 'normative' constructs are in fact, context driven and culturally and historically specific.

1.3.3. Predictors of Psychosocial Adjustment

The degree to which a young person's life is affected by cancer is influenced by a wide range of factors, including cancer prognosis, economic resources, and the type of treatment received (Bauld, Anderson, & Arnold, 1998). Brennan (2001) posits that there may be important psychological mediating factors involved in how, and to what degree, a person adjusts to their cancer experience. These include a person's life trajectory (e.g. goals, aspirations and motivational structure); the nature and quality of their attachments and developmental stage (dependent or not, degree of relationships change); bodily concerns (e.g. sensation, reliability, disability, appearance, fertility and sexuality); self-identity and worth (self-esteem, control, power, autonomy and confidence); and existential beliefs, (spiritual doubt or renewal, beliefs that life is 'fair and rational').

Whilst we can draw on Brennan's social-cultural transition model for guidance, a clear understanding of why some young people cope better than others or predicting those most at risk of poorer psychosocial outcomes has also proved problematic. The majority of studies on the psychosocial impact of AYA cancer are cross-sectional (Barnett et al., 2016). The dearth of longitudinal studies reporting on the long-term impact of psychosocial adjustment means that relatively little is known about how the psychosocial impact may change with different stages of survivorship or over the course of development.

For adolescents, difficulties in parental coping styles have been identified as a significant risk factor (Sanger, Copeland, & Davidson, 1991), as well as poorer mental health prior to diagnosis, or having a negative, depressive attributional style (Frank, Blount, & Brown, 1997). Adolescents with cancers of the central nervous system are also most at risk (Butler & Mulhern, 2005), perhaps given the additional cognitive changes that they endure. Good psychosocial adjustment for young adults is helped by having informal peer support; being able to positively reframe, accept, and normalise their experience; and being prepared for the future (Matheson, Boulton, Lavender, Collins, & Mitchell-Floyd, 2016).

1.3.4. Mental Health

The literature paints a mixed picture with regards to mental health. Several studies suggest the majority of AYAs function well psychologically (Bellizzi et al., 2012; Wicks & Mitchell, 2010), and some (e.g. Roper, Cooley, McDermott, & Fawcett, 2013) have found no difference in rates of depression and anxiety between AYA survivors and controls. Others have found that mental health related quality of life is poorer for AYA cancer survivors than for similarly matched controls (e.g. Smith et al., 2013).

Mental health problems such as anxiety and depression in AYAs (Lauer, 2015; Zeltzer, 1993) are specifically associated with difficulty negotiating a healthy body image (Pendley et al., 1997), and loss of independence and control (Compas, Jaser, Dunn, & Rodriguez, 2012). They can also be linked to difficulties fulfilling the important developmental tasks of adolescence and young adulthood: Increasing independence, construction of an adult identity and the development of romantic and sexual relationships (Havighurst, 1972; Newman & Newman, 2015).

Whether or not a young adult meets the diagnostic criteria for anxiety or depression, experience of cancer is known to negatively affect mood (Reed-Berendt, 2017). AYAs report feelings of anger, of reduced self confidence and self-esteem (Enskär, Carlsson, Golsäter, & Hamrin, 1997; Stinson et al., 2015). Mental health services are the most commonly needed care provision in survivorship, with over 25% of young people requesting it (Wu et al., 2015).

1.3.5. Potential for 'Post-traumatic Growth'

The literature suggests that there are considerable differences in the way that people adjust to cancer and the possibility of hastened death. Brennan's (2001) social-cognitive transition model posits that these differences occur depending on the ways in which their mental models adjust to make sense of their experience. Whilst some AYAs report intense psychological distress, or even symptoms of post-traumatic stress disorder, some AYAs report feeling 'changed' as an individual, of having found meaning in the negative cancer experience, and of achieving greater maturity (Miedema, Hamilton, & Easley, 2007; Tha'er et al., 2015). There is also the potential for this psychological

growth to protect against distress in adulthood. In a longitudinal study using qualitative methods, Zamora et al. (2017) found that adult survivors experienced life altering effects which continued to influence their lives well into survivorship, including personal strength (psychological confidence, emotional maturity), improved relationships with others (family intimacy, increased empathy) new possibilities (having passion for work), appreciation for life (re-prioritisation), and spiritual development.

1.3.6. Peer and Family Relationships

Adolescence (conventionally located between the ages of 12 and 20) is marked by achieving a sense of identity versus remaining stuck in 'role confusion'.

Between 18 and 34 years, the main struggle is described as between the establishment of intimacy (the capacity to form close, stable relationships) and isolation (Erikson, 1968). Emotional separation from parents and the healthy development of strong relationships with peers and potential romantic partners is thought to define the developmental trajectory of young people; determining psychological well-being, healthy functioning, and development of the 'adult self', including core values and beliefs.

For adolescents in particular, time spent with peers during the treatment phases is particularly important for mental wellbeing (Tha'er et al., 2015). But frequent hospital stays, aggressive treatment regimes and disabling side-effects mean that they are often forced to spend time away from their peers and unable to join in with normal activities (Eiser & Clarke, 2007; Enskär et al., 1997), which can lead to marginalisation or 'outsider status' amongst their friends (Lee et al., 2012). Perhaps even more devastating is the emotional or physical withdrawal of peers and partners who are ill-equipped to know how to respond to illness: 81% of 271 young cancer patients stated that peers had been given no support to understand the cancer, it's treatment or side effects (Smith, Davies, Wright, & Chapman, 2007). There is some evidence of variation between the sexes in their experiences of illness, with females more likely to report missing friends and joining in with normal activities, but also more likely to gain positive benefits from the overall experience (Tha'er et al., 2015).

1.3.7. Romantic and Sexual Relationships

Forming intimate emotional and sexual relationships is a highly meaningful aspect of human life. Starting to establish such relationships is one of the critical developmental tasks of this life stage (Rauer, Pettit, Lansford, Bates, & Dodge, 2013; Erikson, 1968), associated with overall identity development and sense of self. For AYAs, this will mean being currently involved or thinking about becoming involved in intimate romantic and/or sexual relationships (Biro & Dorn, 2005).

For young cancer survivors, navigating a romantic and/or sexual relationship is one of their most significant concerns (Yi, Kim, & Sang, 2016). Although cancer does not affect every young person's relationship, studies looking at overall psychosocial functioning suggest that they experience challenges or dissatisfaction with their intimate relationships (Bolte & Zebrack, 2008; Gray et al., 1992), which may be related to a higher than normal expectation for relationships (Thaler-DeMers, 2001).

Cancer in childhood may also affect intimate relationships well into adulthood. Adult survivors report pre-occupation with relationships, dependence on parental figures and avoidance of interactions involving conflict (Joubert et al., 2001). This may explain the finding that survivors of childhood cancer are less likely to marry (Langeveld, Stam, Grootenhuis, & Last, 2002) or find a life partner (Wengenroth et al., 2014) compared to siblings and peers.

Understanding how intimate relationships impact on and are affected by cancer appears to be of importance to psycho-oncology. With relationship status affecting people's ability to cope with cancer (Smith et al., 2013, suggest that single AYA cancer survivors report poorer mental health than those in committed relationships), and evidence to suggest that cancer impacts negatively on people's existing relationships (Bellizzi et al., 2012), it is clearly an important area of research.

This study will focus on the impact of cancer on romantic and/or sexual relationships for young people. Over the last 30 years the impact of cancer on sexual functioning for young adults has been well documented (Acquati et al., 2018; Arden-Close, Eiser, & Pacey, 2011; Hannah et al., 1992; Heiney, 1989;

Tuinman et al., 2010; Zebrack, Foley, Wittmann, & Leonard, 2010), but romantic relationships (and sexual relationships as *part* of them) have received relatively little attention. Given their importance, both as a developmental task of adulthood and a protective factor during the cancer experience, they are now beginning to be recognised as an important area for psycho-oncology.

1.4. Literature Review

To delineate what is known about intimate or romantic relationships for AYA cancer survivors, a systematic narrative review of the current literature was conducted. Whilst many papers in the wider body of literature make reference to how cancer can impact on young people's romantic and/or sexual relationships (Sodergren et al., 2017; Warner et al., 2016), the papers selected for review are those which focus solely on young people's intimate relationships, how they might be affected, and how this integrates with other aspects of young people's development.

1.4.1. Search Strategy

A variety of databases were searched (PsychInfo, CINHALL plus, Academic Search Complete, Child and Adolescent Studies and Science Direct) in order to identify published literature on romantic and sexual relationships for adolescents and young adults with cancer. Articles were abstracted using the words "neoplasm" or "cancer," combined with phrases reflecting the population and constructs of interest (i.e., adolescent, teenager, young adult, romantic, sexual or intimate relationships) in the title, abstract, or keywords.

1.4.2. Overview of Results

417 articles were found using the search terms across all databases, of which 387 were excluded on the basis of irrelevancy, leaving 30 to be reviewed. Studies were included if they explored romantic or romantic and sexual relationships for adolescents and/or young adults (aged 14-39) with cancer. Studies which focussed only on sexual functioning were excluded. No studies were excluded on the basis of location, and all types of cancer were included. All articles selected were published in English between 1989 and 2017. Due to the relative paucity of research in this area, no particular methodology was

excluded, and there was no distinction made between the stages of AYA 'survivorship'. The reference lists of the identified papers were checked and relevant papers included in the overall review.

The search produced a range of results (reviews and retrospective empirical studies) using a range of methodologies. Four recent empirical studies explored how cancer had affected the quality and nature of romantic relationships for recent AYA cancer survivors of both sexes; one using quantitative methodology (Geue, Schmidt, Sender, Sauter, & Friedrich, 2015), two others using qualitative methods (Robinson, Miedema, & Easley, 2014; Stinson et al., 2015), and one using mixed methods (Robertson et al., 2016). Another qualitative study focused on the romantic/sexual relationships of young male survivors of testicular cancer (Carpentier, Fortenberry, Ott, Brames, & Einhorn, 2011). Appendix A provides a summary table of empirical studies for easy identification.

One review paper gave an overview of the experiences of male cancer survivors' romantic relationships (Carpentier & Fortenberry, 2010), another on the experiences of dating (Hamilton & Zebrack, 2011) and an article written by three female cancer survivors provided a narrative account of how cancer impacts on identity formation in respect of relationship building (Tindle, Denver, & Lilley, 2009). Just one empirical study looked specifically at the experiences of people *in relationship* with young adult cancer survivors; specifically the experiences of male partners of breast cancer survivors (Friedus, 2017).

There was very little research into the diverse experiences of AYA cancer survivors in terms of sexual orientation or ethnicity. Just one study (Russell, Galvin, Harper, & Clayman, 2016) looked at how LGBTQ survivors' relationship experiences and needs might differ from those of heterosexual survivors. All studies included samples taken from predominantly white, relatively wealthy Western populations (Canada, Germany, USA, and Australia), but none were conducted in the UK.

Furthermore, the majority of studies included in the review dealt primarily with AYAs who were already in relationships. Only Carpenter (2011), in her study of

young males with testicular cancer, made any comparison between young people who were single and those who were partnered.

Four primary studies (Gerhardt, Vannatta, Valerius, Correll, & Noll, 2007; Thompson, Long, & Marsland, 2013) and one review paper (Thompson, Marsland, Marshal, & Tersak, 2009) explored the romantic relationships of *childhood* cancer survivors (aged <14) who have since entered young adulthood.

A relatively substantial body of literature dealt mainly with sexual relationships and sexual functioning of AYA cancer survivors. Although extremely relevant and often an important aspect of romantic relationships, they do not encompass the holistic nature of romantic, intimate relationships in the broader sense. They have therefore been summarised for information but excluded from detailed review.

1.4.3. Initiating Relationships

Cancer and its treatment may affect the normal development of new relationships in adolescence and young adulthood (Stinson et al., 2015). Several studies suggest that the physical effects of cancer and its treatment (especially fatigue and nausea) can prevent young cancer sufferers from participating in peer activities, inhibiting normal social interaction where new relationships can develop (Robertson et al., 2016; Robinson et al., 2014; Stinson et al., 2015).

Approaching relationships may be complicated by fears and uncertainty about disclosing their cancer history to potential partners, in case of negative reactions. Young people still undergoing active treatment worry about the 'different dynamic' in new relationships because of their different needs, the stigma of illness, and fear scaring potential romantic partners with the reality of cancer and its challenges (Stinson et al., 2015). These worries can lead to some young people avoiding relationships altogether, depriving them of companionship, intimacy and support (Carpentier et al., 2011; Hamilton & Zebrack, 2011).

Other studies point to the negative effects of cancer on body image, and how this may reduce confidence to start new relationships. Young people are already naturally concerned about how they appear in the context of puberty and developing sexual maturity. Young cancer survivors have described feeling less attractive and desirable to others, which impedes their self-esteem and confidence in starting romantic relationships (Carpentier & Fortenberry, 2010; Stinson et al., 2015). Certain cancers may be more impactful on body image and self-esteem than others, depending on the location of the disease and the after effects of treatment (e.g. scarring in intimate areas). For young men surviving testicular cancer, one of the most common cancers for AYA men, the loss of or damage to body parts with strong associations with masculinity, attractiveness, and fertility can cause particular problems which can deter them from entering into new relationships (Carpentier et al., 2011).

Other psychological barriers to starting new relationships have included fear of disclosure about potential fertility problems and the cancer itself (Carpentier et al., 2011; Robertson et al., 2016). For single testicular cancer survivors, feeling 'different' in the wake of their cancer experience was not the broadly positive experience their partnered peers described. They were more likely to experience worry about how their cancer history and possible infertility would be perceived by future romantic partners. Loss of a testicle led to feelings of vulnerability and of feeling 'incomplete' as a man, and of feeling more hesitant and unsure during sex.

For younger adolescents (aged 12-17) dating was put 'on hold' whilst they focused on getting better, and many worried that their cancer would 'put off' future partners, because of reduced attractiveness. Parents of adolescents worried that the cancer experience would affect their experience of sexual relationships, and whether other teenagers would find them attractive 'with scars or missing limbs'. Both parents and adolescents were worried about future effects on infertility (Stinson et al., 2015).

Being single *at the time of diagnosis* appears to carry particular risks and vulnerability for poorer psychosocial adjustment, even if young people go on to form relationships in the future. In a review of the literature for testicular cancer

survivors, single survivors reported higher levels of cancer-related stress symptoms than their partnered counterparts. Young men who were single also reported more problems with their sexual functioning compared to young people who were partnered (Carpentier et al., 2011).

1.4.4. Being in Relationships

Using a standardised questionnaire, Geue et al. (2015) conducted a cross-sectional study assessing the relationship quality, sexuality and sexual support needs of 99 AYA survivors of cancer aged between 18 and 45. Overall, they found similar levels of relationship satisfaction in AYAs and the age-matched general population. Two thirds of AYAs reported having sex less often than before their diagnosis: 70% of these were women, and about a 3rd found this problematic. A quarter of AYAs were dissatisfied with their physical attractiveness and sexual responsiveness, and overall women described themselves as more in need of professional support around sexuality than men. Young people who were more fatigued were more likely to have sexual functioning needs.

Despite Geue's finding that there is no significant difference in relationship satisfaction between AYA cancer survivors and AYAs in the general population, studies using qualitative methodology were able to explore the constructs in greater depth. Several found that many young cancer survivors experience dyadic changes as a couple; associated with significant challenges and the potential for greater intimacy (Robertson et al., 2016; Robinson et al., 2014).

1.4.4.1. *Difficulties and challenges*: Robertson et al. (2016), found that 50% of young adult cancer survivors in relationships had experienced difficulties in their relationship over the previous month. For a majority (75%) of young people, arguments were frequently linked to a reduction in sexual intimacy; due to a lack of sexual interest and reduced frequency of sexual activities. Whilst medication and fatigue are thought to have some impact on sexual desire, most young people put the decreased frequency down to changing perceptions of their own body.

The same study also found that a *lack of communication* around changing sexual desire was another difficulty for this age group, and often led to conflict. Young people found that they were not able to confront challenges in the same way as they had before, often because partners were afraid of doing so in the way they had before their partner's cancer diagnosis. Linked to these changes in communicative patterns is the emergence of different needs in the context of cancer (e.g. need for comfort; physical care) which can place the relationship under significant strain, particularly if a partner is unable to meet them. Conflict was also attributed to other aspects of sexual life: One young person mentioned that increased attention from other girls after his diagnosis had caused jealousy and difficulties between him and his partner.

Similarly to Robertson et al. (2016), Robinson et al. (2014) found that cancer in young adulthood presented a significant challenge to intimacy, which they conceptualised as comprising of sexual *and* emotional closeness in relationships. They critiqued previous literature, which evaluated intimacy solely in terms of frequency of sexual intercourse. Instead they utilised Hordern's (2008) broader and more nuanced understanding of intimacy in relationships; which incorporates sharing, closeness, touch, communication and self-esteem as important elements; and strongly linked to well-being. Contributing to this loss of intimacy was a general loss of physical desire; through the use of anti-depressants, general fatigue, fear of hurting one's partner or future children with chemotherapy drugs in the body. The psychological consequences of having cancer (e.g. loss of control, sense of invincibility, changing priorities) places strain on the relationship as a whole and reduces emotional and sexual intimacy.

The study also found that intimacy was affected by changes to the body in general (e.g. weight gain/loss, scarring, hair loss) and sexual organs (e.g. a 'shrunk vagina', loss of testicle or breast, hormonal changes, bleeding, loss of erectile function) and the corresponding changes to body image.

Loss of previous intimacy with a partner, coupled with the mental strain of having cancer can be particularly challenging for the young cancer patient, leading to what one described as 'depression and self-pity'. This can be

particularly difficult if problems in the relationship are not talked about, which was a relatively common occurrence. Some participants found that their partners were not able to deal with their own stress in response to the cancer, or that they stopped providing support at moments when it was still very much required (e.g. after chemotherapy ended), which led to increased conflict and stress. One participant's partner left them during active treatment, which was described as highly distressing and traumatic.

1.4.4.2. *Protective Factors*: Being in a supportive relationship can be a protective factor for AYA cancer survivors in terms of psychological wellbeing (Carpentier & Fortenbury, 2010; Robertson et al., 2016; Stinson et al., 2015), and dating can also be a significant source of support (Stinson et al. 2016). For many, the cancer experience had actually strengthened their relationships by bringing them closer (Robertson et al., 2016) and allowing them to develop an adapted intimacy, encompassing 'more than just sex' (Robinson et al., 2014). The experience of tackling something challenging together, the intensity of confronting one's own mortality, and of being supported by one's partner all played an important part in this increased intimacy. Interestingly, the 'stage' of the relationship did not seem to matter.

Carpentier et al. (2011) also found that the experience of cancer was a positive influence on their relationship. Many felt different from others as a result of their experience, reporting changes in their values and the way they viewed life. For partnered survivors, this meant taking their relationships more seriously than they had before, with one feeling that he felt more focussed on 'settling down', which was positive for his relationship.

1.4.5. Childhood Cancer Survivors

Prior to 2009, any research into the romantic relationships of childhood survivors of cancer tended to focus on the attainment of relationship outcomes (e.g. rates and ages of cohabitation and marriage). The results have been mixed, and usually cover wide age ranges which may obscure developmental differences in psycho-social adjustment. Several suggest delays in the formation of romantic or intimate relationships, including lower rates of marriage and cohabitation, older ages at first marriage, and romantic relationships of

much shorter duration (e.g. Rauck, Green, Yasui, Mertens, & Robison, 1999), whilst a smaller number of studies report no effect of childhood cancer on dating and marriage outcomes (e.g. Byrne et al., 1989).

The search terms identified four empirical studies specifically focused on the romantic relationships of childhood cancer survivors who had since entered adolescence or young adulthood. In a matched pairs comparison study of emerging adults, Gerdhart et al. (2007) found no difference in terms of dating status, habitation with parents or desire to marry or have children, despite cancer survivors participating in fewer activities. The type of disease and treatment appeared to have very limited association with outcomes.

In another quantitative study, Thompson et al. (2009) sought some clarity over these inconsistencies in the literature by moving beyond measurement of relationship milestones to measurement of relationship *quality* and relationship difficulties. Similarly to Gerhardt et al. (2007), she found that survivors of childhood cancer did not differ from demographically similar controls in terms of their satisfaction with, conflict in, and duration of romantic relationships. However, they did report fewer romantic relationships and greater distress at relationship end. AYAs were more likely to experience relationship difficulties if they had trait anxiety, were subject to more severe treatment, or were diagnosed later (i.e. in adolescence).

This study was critiqued by Lehmann (2010), for its poor design, including use of an inappropriate measuring tool for the selected sample. She advocated the use of more deliberate designs to study this impact of childhood cancer on emerging adult relationships, including longitudinal designs, larger sample sizes and a focus on specific cancer sites. Several years later she conducted a study of her own (Lehmann, 2016), comparing childhood cancer survivors to similarly matched peers using a web-based questionnaire. Unexpectedly, she found that childhood survivors were unlikely to experience any differences in body image or psychosexual development to their matched peers. Similarly to Thompson (2009), she found survivors of childhood cancer and controls to have comparable levels of body image, body dissociation, sexual satisfaction.

In a qualitative study, Thompson et al. (2013) interviewed 18 childhood female survivors about their experiences of relationships in emerging adulthood. Many perceived themselves to have a more mature perspective on life, following their cancer. Sometimes this effected their relationships in a positive way; they no longer argued over 'petty' concerns. But single young people felt it might hinder them from finding a partner of a similar age who was as emotionally mature and who shared a similar life perspective. When disclosing the cancer history, many felt surprised and disappointed by the reactions of peers and romantic partners, who showed a lack of interest or an unwillingness to talk about it in any detail. Disclosing to peers was markedly different from disclosing to people in their 30s, 40s and 50s, who were more likely to take an active interest. One suggested it was perhaps 'too much reality' for their peers in emerging adulthood to take in. This experience usually led to an unwillingness to disclose in the future, for fear that it would drive potential romantic partners away. Some childhood survivors commented on a general avoidance of conflict or a reluctance to share intimate thoughts or feelings with romantic partners, perhaps out of a fear of getting 'too close' to people, which often led to conflict in their relationships. Body image concerns and worries about infertility were also cited as issues with the potential to cause relationship difficulties.

1.4.6. Sexual Functioning

Whilst research into the impact of cancer on AYA's romantic relationships is a relatively recent development, there is over 30 years of literature concerned with the impact of cancer on AYAs sexual functioning (Chambas, 1991; Klopovich & Clancy, 1985). A range of quantitative and qualitative research now exists to suggest that the *majority* of adolescents and young adult cancer survivors will experience impairment in sexual functioning (Wettergren et al., 2017) and that this can occur whether the cancer first appeared in young adulthood (Aubin & Perez, 2015; Bolte & Zebrack, 2008), or in childhood (Ford et al., 2014; Jervaeus et al., 2016; Van Dijk et al., 2008; Zebrack et al., 2010).

Studies report that cancer has detrimental effects on erection, ejaculation, and orgasm for AYA men. For females, cancer is associated with decreased desire, but there appear to be mixed findings with respect to arousal, orgasm, and satisfaction (Stanton, Handy, & Meston, 2017). It is also suggested that

relationship status may play a part in sexual functioning. Single testicular cancer survivors report worse satisfaction with erection and orgasm and lower overall sexual satisfaction as compared with partnered survivors, despite higher levels of sexual desire (Carpentier & Fortenberry, 2010).

Knowing about changes in sexual functioning is particularly important because we know it can cause problems in intimate relationships, both because of the potential to generate conflict, and as a barrier to feelings of closeness and intimacy with partners (Robertson et al., 2016).

1.4.7. Partner Perspectives

The review found there to be a distinct lack of research from the partner perspective, with just one empirical study looking specifically at the experiences of men in relationships with breast cancer survivors (Friedus, 2017).

In this retrospective study, Friedus (2017) interviewed men who had committed to relationships with breast cancer survivors under 50. The majority were accepting of their partner's cancer history and their views towards their partner had not changed after they were told. Their partners had usually disclosed their breast cancer history relatively early (by the 3rd date) which was important, providing the men with important information which shaped their developing feelings towards their partner. Sometimes the disclosure contributed to the men feeling more strongly about their new partner, resulting in new feelings of admiration and respect. Knowing the information early also helped the men feel in control. Armed with 'the facts' (e.g. about future fertility) helped them to make choices about how best to proceed with the relationship.

For men who did not have prior experience of cancer or of working in the medical field, talking to their partners about cancer was especially difficult. Some had concerns about their partner's possible infertility or the potential of cancer to be passed on to future children. However, the men in this study did not let the cancer discourage them from continuing the relationship. The majority of men in the study reported that their sexual relationship and physical intimacy had been affected, but usually because of decreased body confidence in their partner, rather than any change in their levels of desire.

Nearly all felt the cancer had generally had a positive impact on their relationship. They reported a new found resolve not to feel stressed about minor irritations, and a new appreciation for life itself. Many reported that the cancer had taken an 'emotional toll' on them as a couple, because of the additional pain, stress and worry than their partners had to endure, but the men did not spend a lot of time managing their distress on a daily basis. When they did, they tried to be 'logical' about what could be practically attended to, rather than letting it 'take them over' emotionally.

1.4.8. Summary and Conclusions

The review found that many AYAs with cancer experience challenges and strains on their romantic relationships, that the cancer experience can interrupt their normal development, and that problems maintaining intimate relationships may persist into survivorship. Although not all young cancer survivors will experience difficulties in their relationships, the majority will suffer reduction in their sexual functioning, which can negatively affect their relationships.

The review also suggests that romantic relationships are a significant source of support for AYAs with experience of cancer, and that people in relationships cope better with the psychological and emotional demands of cancer. However, cancer can also be a source of conflict between couples; either exacerbating existing conflicts or generating new ones; and these are often related to changes in sexual functioning and/or difficulties in communication around this. Experiencing cancer can also lead to a re-evaluation of life and a change of priorities, which can also affect relationships. This can either hasten the end of conflictual relationships or help to mitigate conflict and bring couples closer together. Single people fare less well than those in relationship in terms of their psychological adjustment to cancer and may be at particular risk of poor mental health.

1.4.9. What is Lacking?

With just four primary studies dedicated to understanding romantic relationships for AYAs in early cancer survivorship, the area remains under-researched. Few studies have differentiated between type of cancer population, or different age

groups within the AYA range. Although some are dedicated to exploring how young males and females might be affected, none investigate how cancer might affect young men and women differently. Although we know that cancer impacts on young relationships by exacerbating conflict, little is understood about complex relational processes which might occur when a young couple face a life-threatening illness, and how this might be related to current relationships with parents or previous attachment patterns. We do not know if and how a 'mature' relationship is affected differently from a more newly established one, and we still have more to understand about the increased risks to psychological wellbeing faced by single young people. No studies have so far been conducted with young people in the UK, but with other comparable populations.

Studies are also very limited with regard to socio-economic and ethnic diversity; all have been conducted with English speaking participants. An evaluation of a clinical audit conducted in India concluded that 1 in 3 young cancer survivors experienced issues related to intimate relationships, such as body image problems and peer group isolation (Salins, Vallath, Varkey, Ranganath, & Nayak, 2012), but issues pertinent to young people (sexuality, infertility and relationship concerns) are not being properly addressed. Perspectives on relationships and fertility are likely to differ significantly in different cultural and social contexts, which limits the representativeness of any findings cross-culturally.

Parental perspectives are lacking, particularly input from fathers. Stinson et al. (2015) looked at parental perspectives but did not assess the demographic characteristics of the children associated with their parent participants, so cannot comment on how a child's age, gender, diagnosis, etc., may have influenced a parent's responses. Romantic partners of AYA survivors are also woefully under-represented (Friedus, 2017), and no study has sought the 'couple' perspective, by interviewing both people in the relationship together, even though there are several such studies for 'adult' cancer survivors (Giese-Davis, Hermanson, Koopman, Weibel, & Spiegel, 2000; Manne, Badr, & Kashy, 2012; Manne et al., 2006).

1.4.10. What Might be Useful for Future Research?

Longitudinal studies of childhood cancer survivors suggest that healthy relationships are key to good quality of life in survivorship. Greater understanding of how AYA cancer survivors maximise the gains to their relationships and minimise the conflict has important implications for supporting them through the rest of their lives. Future study designs should therefore be tailored to understand underlying reasons behind different relationship trajectories, so that opportunities for resiliency and building supportive relationships can be realised. In particular, the need to evaluate the needs of male survivors who report difficulty with romantic partnerships has been cited (Carpentier et al. 2011).

This has prompted calls for more specific questions from oncology health professionals to identify who is most at risk of adverse effects and to adequately support people who may already be experiencing difficulties in their intimate relationships or with sexual functioning (Hautamäki-Lamminen, Lipiäinen, Beaver, Lehto, & Kellokumpu-Lehtinen, 2013).

Robertson et al. (2016) highlight the need for more understanding of how single people and those in relationships might be affected differently by their cancer experiences and call for further research to look at a longer time period (they only asked people about their relationships over the previous 30 days).

For single survivors, it is suggested that reduced confidence and fears about cancer disclosure make it harder to find a partner, whilst a changed attitude towards the brevity of life and changing priorities make it more important. Further clarity about how single cancer survivors approach dating and navigate early relationships would also be of importance to the literature.

1.4.11. Problems with Existing Research

Researchers have pointed to more general problems with the existing psycho-oncological research which is useful to consider before embarking on any further study. Firstly, that current evidence on the AYA group is often based on childhood cancer survivors who have since entered into this age group, rather

than young people diagnosed and treated as adolescents (Jones, Parker-Raley, & Barczyk, 2011).

Secondly, are the numerous variables to consider, which make designing a methodologically robust research study extremely challenging. Adolescent and young people (even those of a similar age, sex, and/or cancer site) are likely to have more differences between them which affect the development of their romantic relationships, and only have the experience of cancer in common (Grinyer, 2009).

Thirdly is the term 'AYA' in research. The lengthy transition from childhood to adulthood in Western cultures is a period of complex biological and psycho-social development, and this is a very heterogeneous group (Ramphal et al., 2011). The term 'AYA' clearly has some utility in being able to broadly distinguish this group from children, who may be completely dependent on adults and less cognitively and emotionally able, and older adults who may have dependents of their own and be more settled in life. Nevertheless, its usefulness as a construct for research purposes is limited, and there is also substantial variability in the age ranges used by researchers to describe it, making meaningful comparison between studies particularly difficult.

1.4.11.1. 'Developmentally Specific' Research?

Researchers have called for the construct of 'AYA' to be more explicit and globally defined (Geiger & Castellino, 2011), and for psycho-oncological research to be tailored to different 'developmental stages' in order to elucidate the subtle aspects of adjustment effect which affect quality of life (Joubert et al., 2001).

Any attempt to be 'developmentally specific', however, is also problematic. Splitting this time period meaningfully by 'developmental stage' risks reification of social constructions of human development which are dependent on individual belief systems and wider social and cultural context. Recognition of broad age ranges marked by important life changes may be important and increase the utility of the research, but these life changes or developmental changes are neither fixed nor inevitable. Any developmental definition in AYA years can only be linked to the particular structures, normative expectations and institutions of contemporary developed nations of which we have some

knowledge.

1.4.12. Issues of Priority

Given the relatively small body of literature and the well documented methodological problems associated with the topic, it seems particularly important to prioritise the areas of importance, whilst acknowledging what is feasible within the overall project parameters (ie. funding, scale etc.). There are five points raised in the general critique above which I think are particularly important to address. Firstly, the lack of studies in the UK, and therefore the importance of conducting a study on this population. Secondly, the developmental heterogeneity of the 'AYA' age group, and the importance of understanding the particular needs of young people at different stages within this very broad age bracket. Whilst acknowledging that being 'developmentally specific' is not possible, focussing on a shorter time period within the 'AYA' years might start to address some of the variation. Thirdly is the lack of knowledge we have about how young men and young women might be affected differently in the context of their cancer experience, and the lack of understanding about how single young people cope during their cancer experience, and in instigating new relationships after cancer. These points may be of particular clinical relevance as we know that young single men might be at greater risk of psychological distress (Carpentier et al., 2011). Fourthly is the lack of detail about which aspects of romantic relationships in particular are affected by cancer in young adults, and which might act as protective factors. Although the adult literature has engaged with issues of communication (Manne 2006), there is much we don't know about how young adult relationships might be affected differently from older adults, or not. Until we understand more, young people may be disadvantaged when it comes to receiving well informed support.

1.5. Rationale and Aims for the Current Study

Given the concerns of young cancer survivors about forming romantic and sexual relationships, the importance of intimate relationships to the psychosocial health of adolescent cancer survivors, and the implications of interpersonal difficulties in later life, further understanding of how relationships develop and are maintained for young cancer survivors seems to be of

particular importance. The following study aims to facilitate greater understanding of this by examining young adult cancer survivors' perspectives on romantic relationships in survivorship, drawn from a UK wide population. Doing so will hopefully target areas of unmet need and guide those working with them as they navigate the challenges of cancer survivorship in young adulthood.

Previous research into romantic relationships has explored the experiences of younger adolescents aged 12-17 (Stinson et al., 2015) and others make no distinction between the different ages in the 'AYA' period (Geue et al. 2016; Robertson et al., 2016; Robinson et al. 2014). Most of the focus has been on those already in committed relationships, and there is a lack of understanding about the particular challenges or benefits of cancer to the *development* of young people's relationships, or how the cancer experience affects 'single' young people, and/or those in the early stages of dating. This study will aim to add to the existing literature by focusing on young people in 'emerging adulthood', a developmental category first proposed by Arnett (2000, 2001) for people from the late teens to late twenties. The period is characterised as a period of transition and flux, when young people go through a prolonged period of identity and role formation, with the ability to develop intimacy with significant others a key element.

Sampling in this way will act as a useful comparison to Stinson's study on adolescents, with the intention of capturing the experiences of more young people in the early stages of relationships.

Adolescence and young adulthood is a time when gender identity is still forming and developing, and young men and young women may well take different approaches to negotiating relationships due to societal expectations of how they are expected to 'perform' their gender role. The conventional discourse that young women are more concerned with love and romance and young men with fulfilling sexual desire is particularly powerful (Kehily, 2007). For example, physical changes which lead to young people being perceived as younger than they really are (Jones et al., 2011), may affect men more negatively than women. One recent study focuses on how gendered identity affects cancer

survivors' concerns (Pounders, Stowers, Wilcox, Love, & Mackert, 2017), and suggests that greater understanding of how this affects young men and young women would be of benefit. This study will aim to add to the literature by exploring the experiences of male and female participants through the lens of 'gender'.

1.5.1. Research Questions

Drawing on the findings of the literature review, and what is missing from the current body of research, the current study will aim to answer the following research questions:

1. How are romantic relationships affected by cancer for AYA cancer survivors currently in 'emerging adulthood'?
2. How are people in relationships and single 'emerging adults' affected differently by the cancer experience?
3. Are young male and female cancer survivors affected differently by their experience of cancer as they engage in romantic relationships? If so, in what ways?

2. METHODS

2.1 Overview

This chapter will discuss the epistemology, methodology and method used to address the research questions. It will begin by articulating the ontological and epistemological positioning which has informed the choice of methodology. Next, the design will be outlined, including the procedures used for participant selection, ethical approval processes and data collection. Finally, the approach to data analysis will be described.

2.2 Ontological and Epistemological Positioning

Prior to undertaking any kind of quest for knowledge, it is vital to consider one's ontological and epistemological position in order to contextualise the foundations on which the knowledge is sought (Willig, 2008). Ontology refers to the assumptions made about the nature of reality; the world and its phenomena (Chamberlain, 2015); epistemology refers to *how* we can come to truth or knowledge, or what it is possible to know (Barker, Pistrang & Elliot, 2003).

Two opposing ontological positions have dominated the social sciences for much of the 20th century. Realism, which posits that there is one independent 'truth' which is possible to know, and social constructionism or relativism, which argues that there are multiple realities which will always be mediated by context (Berger & Luckmann, 1967; Burr, 2003; Gergen, 1985, 1999). Critical realism is a third ontological position which lies between realism and relativism (Willig, 2012). It posits that there is a truth, but that it is not ever possible to know it from our culturally contextualised positions. Adopting this stance allows an emphasis on both the material realities of people's lives *and* the social contexts that shape and govern them.

Across healthcare, adoption of a realist (positivist) approach to knowledge production is widespread. Empirical approaches which assume a realist epistemology suggest it is possible to 'know' reality and the quality of this knowledge is dependent on the sophistication of the instruments through which we study phenomena (e.g. standardised psychological screening measures).

Conversely, constructionist epistemologies suggest that there is no one truth to uncover, and that researchers are in fact *creating* knowledges through their pursuit of it; 'knowledge' of the world is only a product of how we come to understand it (Burr, 2002).

This study will adopt a critical realist ontological and epistemological position. Whilst acknowledging that cancer is a disease which has a real impact on the body and mind, the *meaning* of cancer for each person is idiosyncratic and mediated by numerous contextual factors. While there may be a reality to people's experience of cancer, a critical realist position accepts that this reality can never be known, and any attempt to glean this information will always be complicated by the multiple assumptions and values with which we are imbued, as researchers and participants. Adopting this position means accepting that the pursuit of knowledge in this area can never be objective, but we can attempt to ascertain something of the truth nonetheless.

My research questions do not require me to prove a theory, or to ascertain causality. Instead, they seek to explore meaning about romantic relationships and cancer in young people, for which a qualitative methodology is well suited (Denzin and Linton, 2005a). As a subjective, reflexive researcher, I will be applying a 'bottom up', inductive reasoning approach to the data to create 'a truth' about young people's romantic relationships in the context of their cancer experience. Whilst doing so, I acknowledge that this will only resemble something close to the reality of people's experiences, through the medium of their socially constructed 'lens' and mine. Looking for patterns in people's experiences will give us a sense of the discourses which both inform and are formed by people's experiences.

Transcending ontological and epistemological concerns, I consider it most important that the research is of use to young people with cancer and the people supporting them. The study's design intends to tackle the growing gap between research and what is important to young people (Marks, 2009), by addressing questions of relevance about young people's experiences.

2.3 Design

As this specific area of young people's cancer experience has received relatively little attention, I aimed to take an exploratory approach which focussed on participants' meaning-making activities, which is facilitated by qualitative methods (Reavey & Johnson, 2013; Willig, 2013).

2.3.1 Choosing a data analysis

Under an overarching qualitative methodology, there were several possible ways to approach my data analysis. Broadly speaking, a more descriptive analysis would have intended to capture the voice to the young people and their account of their experience of cancer. However an interpretative analysis goes beyond the surface, and what is obvious in the data in an attempt to make meaning out of why such particular words/stories were told, drawing on contextual or theoretical understanding to gain a deeper level of understanding. Bearing my particular research aims in mind, my first requirement was to conduct some form of interpretive analysis which also captures the experiences of my participants. My interpretative aspect, for example, might include drawing on social-political contexts to understand why a female cancer survivor might frame her account of her cancer experience differently from a young male cancer survivor.

Possible approaches using some form of interpretative analysis included Grounded theory (Charmaz, 2006), Interpretive Phenomenological Analysis (IPA) (Smith et al. 2009), a Discourse Analysis (Potter & Wetherell, 1987), or Thematic Analysis (Braun and Clarke, 2006). All of these approaches look for patterns across the data, but in different ways and with different foci.

IPA's is a phenomenological approach which is primarily concerned with the participant's view of the world and the meanings they attach to their experiences. It follows a formulaic, dual interpretative process in order to analyse this; the researcher is trying to make sense of the participant making sense of their world in a clearly outlined two stage process (Smith et al, 2009). For my analysis, IPA would be beneficial in allowing a focus on the differences between individual accounts, and clearly lay out the dual analytic process. However, it is argued that this dual approach can dilute the richness of the

analysis by splitting it into two separate processes, and that the methodology can be didactic and allow little room for creativity (Braun & Clarke, 2013). Furthermore, its phenomenological epistemological position is distinct from my own critical realist epistemology.

Grounded Theory (GT) is concerned with developing theory from the 'ground up'. Rather than using the traditional 'hypo-deductive' method, it aims to develop theory from people's socially and contextually driven experiences. For this research, using GT would ensure that young people's experiences were clearly represented and that I was not merely drawing on existing theories to make sense of their experiences. However, I am not aiming to develop a theory to account for the process of adjustment but instead to identify some of the challenges they face in the context both of their own growth and development and the social milieu in which they are located (family, friends, peers etc.). Therefore GT was not deemed suitable in this instance.

A Discourse Analysis is concerned with what language does. In this case, it might have focused, not on the experiences of young people with cancer, but on the socially patterned meanings around their construction of these experiences, thinking about their particular position in the world and the possible discourses available to them at this particular point in time. However, given the relative lack of knowledge about the experiences of young people of this age group, and therefore the need for some descriptive analysis, this approach may not be suitable.

Thematic Analysis has the benefit of flexibility, and the possibility of incorporating beneficial aspects of all of the above to suit my aims. In this case, I would aim to offer some interpretation of language use (e.g. when talking about gender), and to process the data in a largely 'bottom-up' way, whilst not losing sight of theories of interest. Or rather, I would be able to identify themes from the data itself, whilst also holding in mind theoretical constructs which could be used to enhance our understanding of these themes. As I am invested in ensuring that the results are useful, a thematic analysis would also have the benefit of ensuring that the results are relatively accessible to all stakeholders in the project, such as young people themselves, and those supporting them.

For these reasons, I chose a thematic analysis with an inductive and constructionist focus as a method for analysis. As it is not aligned with any particular theoretical or epistemological paradigm, thematic analysis is compatible with a critical realist position.

Semi-structured interviews were chosen as the means of data collection.

2.4 Ethics

Ethical approval for the study was sought (Appendix B) and granted (Appendix C) by the University of East London's (UEL) Ethics Committee, and the Teenage Cancer Trust (Appendix D), who supported the recruitment of all participants.

All participants gave written consent in advance, and verbal consent immediately prior to commencing the interview. Verbal and written information was provided to all potential participants to ensure that consent was as informed as possible, and they knew they had the right to withdraw from the study at any time without affecting their relationship with the Teenage Cancer Trust. Confidentiality rules and any exceptions (ie. if they disclosed a risk of harm to themselves or others) were clearly explained.

I was sensitive to the potential distress that might be experienced by participants as they discussed their cancer and romantic/sexual relationships, keeping this in mind at all stages of the research. Potential participants were aware of the subject area in advance, and during the interviews I was alert to any signs of distress, offering to pause or move to another topic area if any were shown. I also thought carefully about how to structure the interview in order to optimise participants' ability to speak freely and comfortably, deciding on a staged approach to help participants 'warm up' with a subject or story they knew well. In doing so, I hoped that participants would not only be protected from harm, but also experience the interview as a useful opportunity to express themselves freely about an area of importance in their lives.

Following each interview I offered a debrief, with the opportunity for participants to discuss how the interview had gone and to speak further about any of the issues raised. Within 48 hours I sent an email to all participants with a reminder of details of a cancer organisation for people in their 20s and 30s (www.trekstock.com). If specific issues had been raised within the interview (e.g. low mood or desire for exercise) I included more specific information that might be of use (see Appendix E). All participants were given my contact details if they wished to talk about the research in the future, and all were informed that they would be contacted with a summary of the findings. It is also planned to disseminate the findings to a wider audience of young people through an open day with the Teenage Cancer Trust.

Information about participants and people they referred to during the content of interviews was anonymised (using pseudonyms) and kept confidential on a password protected computer. Audio recordings were deleted once the transcripts were completed, and I was the only person who had access to the transcripts, which will be destroyed 12 months after the study's completion.

2.5 Research Procedure

2.5.1 Sampling and Recruitment

I aimed to recruit young people between the ages of 18 and 29, who spoke fluent English, and who were no longer receiving active treatment (chemotherapy, radiotherapy, or in recovery from surgery). Initially I aimed to recruit young people who were diagnosed with cancer in adolescence (between the ages of 14 and 19) and who were now aged 20 or over. I was interested in people with any relationships 'status' and who identified with any sexual orientation.

I met with the Head of Support and the Participation Manager at the Teenage Cancer Trust headquarters to discuss the aims of the research and the most efficient way to recruit from their members. Following this meeting, I designed a recruitment flyer (see Appendix F), which was disseminated to all support team managers at Teenage Cancer Trust units across the country. They distributed the flyer to potential participants in person and/or posted it on social media (Facebook).

Eighteen young people contacted me via email to say that they had seen the flyer and were interested in taking part. I returned their email thanking them for their interest and sending them an information sheet (Appendix G) and a consent form (Appendix H) to sign and return if they still wanted to take part. Eleven participants confirmed that they wanted to continue, and returned a signed consent form via email. All met the criteria for the study, apart from age at first diagnosis. The majority (eight) were between 21 and 25 years old when diagnosed with cancer, and only three were between 14 and 19, as originally requested. However, I agreed with my supervisor that extending the age range was acceptable within the aims of the study. In order to maximise recruitment opportunities, there was no limit on the time elapsed since diagnosis. The average (median) time was 3 years, and 10 out of 11 participants were diagnosed between 1 and 7 years ago. For one participant (Adam), 12 years had elapsed since his diagnosis by the time of interview.

Once the participants had confirmed their consent, we negotiated a mutually appropriate date and time to meet in person at the University of East London, or to speak via Skype. Four participants preferred to meet in person, and seven opted to undertake the interview via Skype. When we spoke, permission to audio record the interview was requested, to which all participants agreed.

During the recruiting period (June 2017-September 2017) I aimed to recruit approximately ten participants, with an equal number of males and females. Ultimately eleven young people gave their consent and were interviewed for the study.

2.5.1.1. *Participants' demographic information:* Tables 1 and 2 summarise the key demographic information of the participants².

	Age at interview	Age at cancer diagnosis	Gender	Sexual orientation	Ethnicity
Becky	20	14	F	Heterosexual	White British (Scottish)

² All names are pseudonyms

Sam	24	21	M	Heterosexual	White British (English)
Mel	26	21	F	Heterosexual	White British (English)
Caroline	24	21	F	Heterosexual	White British (English)
Stephen	24	21	M	Heterosexual	White South African
Lee	25	25	M	Homosexual	White British (Welsh)
Zoe	24	22	F	Heterosexual	White British (English)
Oli	24	17	M	Heterosexual	White British (English)
Hannah	27	24	F	Heterosexual	White British (English)
Adam	28	16	M	Heterosexual	White British (English)
Sasha	24	23	F	Bisexual	White British/Slovenian

Table 1. Demographic information on participants

	Type of cancer	Relationship status during cancer treatment	Current relationship status
Becky	Mixed germ cell malignant brain tumour	Single	Single
Sam	Hodgkin's Lymphoma and	Single	Relationship

	Smoldering Myeloma		
Mel	Hodgkin's Lymphoma	Single	Relationship
Caroline	Hodgkin's Lymphoma	Relationship	Relationship
Stephen	Acute lymphoblastic lymphoma	Single	Single
Lee	Hodgkin's Lymphoma	Relationship	Relationship
Zoe	Chondrosarcoma in spine T8	Relationship	Relationship
Oli	Hodgkin's Lymphoma	Relationship	(Different) Relationship
Hannah	Non-Hodgkin's Lymphoma	Relationship	Single
Adam	Brain tumour - Craniopharyngioma	Single	Single
Sasha	Primary mediastinal Large B-cell Lymphoma	Relationship	Single

Table 2. Demographic information on participants

The sample broadly represented the sex ratio of the young people who are diagnosed with cancer (Cancer Research UK, 2018), but not the ethnic diversity, as no non-white participants opted to take part in the research. Participants originated from across the UK (North/South England, Scotland and Wales), apart from Northern Ireland. Five had Hodgkin's lymphoma and two had another type of lymphoma. Four had other types of cancer (myeloma, brain tumour, germ cell tumour and carcinoma). This was broadly representative of the cancers diagnosed in young people aged 15-24: In females, carcinomas, lymphomas and brain tumours account for 65% of all the cancers registered, and in males, germ cell tumours, lymphomas, brain tumours and carcinomas account for 71% of all the cancers registered (Cancer Research UK, 2016).

Three participants were diagnosed with cancer as younger teenagers (aged 14, 16 and 17). The two youngest (Becky and Adam) were not in romantic relationships at the time of diagnosis and did not start a romantic relationship until several years later. One participant (Stephen) had never been in a romantic relationship. Of the remaining participants who were in their early twenties at the time of their cancer diagnosis, six were in 'committed' romantic relationships at the time of diagnosis, and two were single but became involved with romantic partners after the cancer experience. Of the six in relationships during their cancer experience, two were still happily committed afterwards (Caroline and Lee). One participant was unsure of their future as a couple (Zoe) and three had since broken up (Oli, Sasha and Hannah); one during active treatment (Sasha) and two after treatment completion (Oli and Hannah). Three participants entered new romantic relationships after cancer, and all described their relationships in positive terms (Sam, Oli and Mel).

For three young people who were in relationships (Caroline, Zoe and Hannah) cancer arrived relatively early in the lifespan of the romantic relationship (within one year of meeting), and two were still together after cancer (Caroline and Zoe). Others (Lee, Sam and Sasha) had been in a longer relationship (over two years) and one (Lee) was still with their partner at the time of interview.

2.5.2. Data Collection (Interviews)

Semi-structured interviews were guided by the interview schedule (Appendix I). However, questions were used flexibly, and the conversation was guided primarily by participants. As they all had different experiences of romantic/sexual relationships during and after their cancer experience, the format of the interview depended on their individual experiences. I aimed to strike a balance between retaining the broad focus on relationships, whilst also being guided by what participants felt was important to tell me about their experience, with an overall aim to facilitate the conversation and generate their meanings of the experience (Hollway & Jefferson, 2000).

I transcribed audio recordings verbatim, and repeatedly checked the accuracy of the transcription by listening to the recording twice. Notes on the linguistic

content was recorded alongside other semantic material, such as pauses in conversation, laughter, unusual pronunciation, tone, volume and speed of the voice.

2.5.3. Data Analysis

The qualitative data was analysed using inductive thematic analysis in order to identify patterns and themes of interest. Braun & Clarke (2006) suggest a staged approach, as outlined below:

2.5.3.1. *Transcription*: The transcription process was an important start to the analytic process (Braun & Clarke, 2006), allowing me to become familiar with the data. I transcribed the audio transcriptions verbatim at the semantic level using conventions drawn from Jefferson-Lite (Parker, 2005); a transcription key is included in Appendix J for ease of reference. I read each transcript twice to familiarise myself with the material, commenting on points I considered to be of importance or interest (Appendix K). I then compared the transcripts to the field notes made following each interview, where I recorded thoughts and observations to contextualise the verbal material.

2.5.3.2. *Generating initial codes*: This stage involved systematically identifying 'codes' within the text of each interview. Codes can be defined as "a succinct label (a word or short phrase) that capture a key analytical idea in the data" (Braun, Clarke & Terry, p.100). The data analysis programme 'NVivo' was used to record them, grouping them into common clusters for ease of reference. I aimed for 'complete' coding, which involved coding anything and everything of interest or relevance to answering my research questions (Braun and Clarke, 2013). In practice this involved coding data about different types of relationships (e.g. parental relationships, friendships), so that I could compare them to experience of romantic relationships. I aimed to acknowledge and challenge my assumptions throughout; repeated reading of the text and returning to codes after time away from the data helped to achieve this. Although codes were clustered according to broad similarity (e.g. codes about parental relationships) I was careful not to impose any theoretical constructs on the data at this stage and avoid thinking of the codes in these clusters. This process produced 603 codes across the eleven patient interviews.

2.5.3.3. *Searching for themes*: After the transcripts had been coded, I began to group similar codes together, connecting those which were very similar to each other (Appendix L). I then used pen and paper to map out potential themes, drawing an initial 'mind map' to draw out commonalities within the codes to form overarching concepts (Appendix M).

2.5.3.4. *Reviewing themes*: After identifying these broad themes, I read the transcripts again to think about how well these themes fitted with the entire data set. This led to some changes to the initial map (Appendix N). I also started to use extracts from the data to collate into different themes, which led to certain themes being collapsed and new ones being identified.

2.5.3.5. *Defining and naming themes*: In the final stage, I wrote summaries of each subtheme and superordinate theme, and continued to trial different names for each one that appeared to capture their content most effectively. As I began writing the report of the themes, I continued to think about them analytically, making small changes as I worked towards the final written piece. The final summary of the themes is outlined in the following chapter.

2.6. Reflexivity

As a qualitative researcher embedded in a critical realist ontology and epistemology, I recognise the subjective nature of any quest for new knowledge. As a researcher, I will carry a certain set of beliefs, assumptions and values which will influence the decisions I take throughout the research process. In order to be transparent, it is important to orientate the reader to my particular personal and professional position (Braun and Clarke; 2013). In the final chapter I will return to this as I further explore my role in the research.

I am a trainee clinical psychologist who has worked in an NHS service for adults with psychological difficulties related to cancer. Therefore, I have a professional interest in how psychology can be used effectively to support people with cancer and beyond into survivorship. I also hold a professional interest in the challenges of adolescence and young adulthood, both through working with this client group, and my own personal experiences. Subsequent reflections on how this period has shaped my own life have influenced my decision to undertake work with this age group and to conduct research in the area.

I am a White British middle-class woman and the eldest of a large family. Following my training in systemic therapy, I have become more convinced of the importance of relationships, and how relationships between people and contexts often hold the key to understanding psychological functioning and distress.

I have endeavoured to remain alert to how my particular context has influenced my approach to the research, particularly when I came to collect and then analyse the data. I have tried to reflect on this by keeping a reflective journal (see Appendix Q) which has helped me to think about how my personal position has influenced this process.

3. RESULTS

3.1 Overview

In this chapter I will present the research findings developed after following the steps outlined in chapter 2. Firstly, I will situate the data and provide a brief overview of terminology, before introducing and then outlining in detail the four main themes and nine related subthemes constructed from the data.

3.2 Situating and Contextualising the Analysis

As described in chapter 1, early adulthood is a life stage of considerable transition and flux, and the participants in this sample were no exception. Many of the young people developed cancer in the context of change; leaving the family home or moving home, joining new families, forming early romantic relationships and negotiating meaningful friendships. Some described being in several romantic relationships over a relatively short space of time, and all described being interested in seeking a romantic relationship at some point in their lives. None were married or had been married, although several planned to in the future. Many talked about wanting children in the short, medium or long-term future.

3.2.1. Definitions and Terms

Most young people referred to the person they were in a romantic relationship with as either a boyfriend, girlfriend or partner. One young person described their current romantic relationship as non-sexual, and another was not yet engaged in a sexual relationship with their partner. Another preferred not to use the definitive term 'boyfriend or partner', but instead to describe him more ambiguously as a 'friend/lover'. Young people in romantic relationships during their cancer experience differed in whether their romantic relationships involved sex; four of the young people in romantic relationships were engaged in some form of sexual relationship, and two were not.

3.3. Introduction to the Themes and Subthemes

Four themes and 6 subthemes were constructed from analysis of the data, as depicted below in Table 3 and Appendix O.

THEME	SUBTHEMES
Construction of romantic relationships in context	Separation tension and positioning <i>"You want to cut yourself in two"</i>
	Characterisation and comparison <i>"If he was my husband it would be different"</i>
Challenge and change	New parameters and different roles
	Intensification and amplification
Managing others' perceptions	Fighting the illness identity <i>"I'm still me"</i>
	Physical intimacy and sexual attractiveness
Different 'selves' and new perspectives	

Table 3. Main themes and subthemes

3.3.1. Gender Differences

My analysis of the dataset also identified some differences in the way that male and female participants described their experiences of romantic relationships in the context of cancer. As these gendered constructions appeared across all four themes, they will not be presented as a separate theme. Instead, descriptions will be included throughout the analysis.

3.4. Theme 1: Construction of Romantic Relationships in Context

The first overarching theme is related to understanding the construction of romantic relationships within the context of psychosocial development. At a time of crisis, there are tensions between newer romantic relationships and more longstanding relationships with their parents. As expected, romantic relationships were constructed as different from other relationships, and the

cancer experience appeared to highlight and occasionally to impact on this differentiation.

3.4.1. Subtheme 1: Separation Tension and Positioning: “*You want to cut yourself in two*”

All young people described their parents taking varying degrees of responsibility for their care and becoming more involved in their lives. Nearly all described the cancer experience as bringing them closer to their families, whether or not they were close before. Interestingly, many described becoming closer to their same sex parent or sibling. However, many also felt uncomfortable with a perceived set back in their normal developmental trajectory. Others were simultaneously desirous of the freedom they had discovered away from their parents, whilst also craving the special care they received as an ‘ill child’. Some in relatively new romantic relationships at the time of their diagnosis and treatment wanted to maintain some distance between the ‘parental home’ sphere and ‘romantic relationship’ sphere, as if they were different parts of their identity to be inhabited at alternate times. Some descriptions highlighted the tension they felt about inhabiting these different ‘worlds’.

STEPHEN: Um...it was really good...(...)I really like her..um (small laugh) cooking! So it was really nice to have her back again..erm..and kind of take care of me...so it felt..similar to like it did when I was a child I guess (...) but it also felt like a sort of set back...for me being responsible for myself..I’d started to live by myself now..and then have need to have someone else take care of me.

This young person worried about ‘getting used’ to the care received by his mum, as if it would make continued separation from her more painful. His description captures his sense of confusion and ambivalence:

LEE: Once you’ve moved out, it’s hard..to go back..I wanted to have my partner with me as well, so..you’re used to the freedom that (...) and obviously my mum was very worried about me.. and she’d touch me every opportunity, which isn’t a bad thing...and things that you never...it’s those kind of things you’d miss as well...so yeah..I wouldn’t

want to get used to it. As well. In two different ways....I wouldn't wanna get used to it but I'd like to be at home with my partner! So you want to cut yourself in two and just go like that (stretches arms out wide)...Yeah. I wanted to spend time with my m...with Jay...but I also..and my mum wanted me to spend time with them as well.

Another young person craved closeness with her family, but wanted to retain some space and distance from her boyfriend. Whilst she valued the sense of 'normality' he provided, she was content with seeing him sporadically.

CAROLINE: [Re. contact with boyfriend] yeah... and it would have been different if ..he was around.. 'cause I wouldn't have wanted to see him as much...I liked having the distance 'cause it meant I could have my own time to grieve and my own space.

The stress and intensity of the cancer experience could highlight how different sorts of close relationships were positioned *in relation* to each other. One young person described how her boyfriend was now her 'family'; more important than her parents in being able to support her.

ZOE: When I actually got in to hospital I actually had my operation...woke up and I was actually screaming for John [boyfriend]...erm...I then was screaming for my Dad...I was then screaming for my Mum, cause I had no pain relief for a couple of hours.

ZOE: Yeah...I just wanted him [boyfriend]...because he was the only person that could actually calm me down and was actually was...I'd feel stronger when he was stood next to me. When my parents were there it was very pressuring anyway.

For others, it seemed that parents became more important and influential in their lives. Being in a position of vulnerability and returning to a more 'childlike' state meant that parents became more involved with their romantic relationships than they might have done before.

CAROLINE: My mum's always spoken to him one to one as well.. you know: "don't let her 'do' too much..it's too much walking" (...) and then he gets told off from my parents like: "argh you shouldn't have done that with her!"

The caring needs that arose occasionally highlighted a tension between the role of a parent and the role of a romantic partner in young people's lives. But it also created opportunities for validation of the relationship. Care from a partner was seen as a 'good' thing by parents.

ZOE: He had to deal with all the finances...he had to make sure we had everything we needed...and then he proved a lot of people wrong by that point (...) obviously my Dad kept coming round to see if I needed anything..and John would have done it all already..so he was like "oh! – I feel not needed!" (small laugh)...so that was another good thing...but yeah so John's Mum thought that as well.

3.4.2. Subtheme 2: Characterisation and Comparison: "If he was my husband it would be different"

Romantic relationships during the cancer experience were conceptualised in various ways by young people, either through overt descriptions of their important qualities, or by comparison to other types of relationships in their life (e.g. with friends). A romantic partner seemed particularly important in helping young people cope, primarily by being someone to talk to. Many described their partners as a 'rock', an image that brought to mind a steadfast and trustworthy presence during a time of turbulence and uncertainty.

OLI: She...she was very much a 'rock'.

HANNAH: He was such a good support. I couldn't imagine going through it...without him?

MEL: He's been to every appointment since. And... he's a bit of rock to be fair..cause now I go to him.

LEE: To be honest if I didn't have my partner I think I'd have been a lot worse.

Only one young person described being let down by a romantic partner during her treatment. She found this more of a 'negative experience' than the cancer itself.

SASHA: The thing that..became the big thing err..was a friend..a friend slash lover...who was initially very present and then from my perception failed...so that was...that was my shock through this thing...and it ended up overriding the negative experience of the cancer"

Her response also demonstrated the distinction between her romantic partner and her other friends. Even though she had other friends looking after her, his actions took on particular significance. By letting her down when he said he would not, he broke trust between them.

SASHA: I felt it was a betrayal...and at some level abandonment...because he went to look after himself..when I wasn't in a good place...because even though I had everyone supporting me and taking care of me (...) he was one of the first people I told...and when I told him..and made known that I wanted him to be there...he agreed to that!

The strength provided by a partner was conceptualised in various ways. Often as someone to talk to, but also as motivators or advocates when they were feeling emotionally or physically weak.

LEE: Jay passed his driving test whilst I was ill and he would drive me around...and he would spur me on.. [He] motivated me when I was feeling my weakest to like: 'take your tablets'...what are you going to wear today? [But] it wasn't just the kind of doing things for you like getting your juice or taking you round the park...it was just like...someone to talk to really.

SAM: I find...like talking to her about it is quite... she's just genuinely interested and concerned about how I was getting on. I found her really helpful.

ZOE: it was only when John came and I told [him] what had happened...and if *he* hadn't have (...) said "no – you need to say something" I probably wouldn't have said anything when that nurse came in...but I did.

Prior to being diagnosed, several young people felt that people in the medical system did not take their symptoms seriously. Having a partner *believe* them was cited as particularly valuable at that time.

ZOE: It sounds weird but: "I know you're not going insane..I *know* what's going on". Like somebody that actually *believed* me (...) instead of quizzing me about it? (...) just somebody that was sympathetic and actually *knew* what was going on was really what I wanted at the time, because I was struggling...I was really struggling.

As well as being strong and steadfast, supportive partners were adaptive and sensitive to changing needs. For some, this meant providing different sorts of support at different times from joining in with humour to make them feel better, to listening to reoccurring worries.

OLI: one of my party tricks at the time was..if she was next to me, I'd put her hair on top of my head and be like, "right – what sort of hair style should I go for, when I get my hair back?" And we'd do stupid things, like, do a mo-hawk and stuff like that... so she'd, you know, she wouldn't encourage it but she would...she'd be there... to just let me do it (small laugh). So..yeah, she facilitated my..horrible sense of humour about it as well.

For others, the emotional cancer experience led to them showing distress and revealing different sides to their character relatively early in the relationship. Their partner's acceptance of this was also important and affirming.

MEL: He's been to every appointment since we got together...he's seen me have a wobbly in the carpark and he's seen me have a wobbly when I've got in...but then he's seen me come out and I'm back to me.

There were some differences in the way men and women talked about the type of support they needed most. Young men described feeling particularly comforted by having knowledge about the cancer, or having something tangible to 'do', more frequently than women. A need for tangible 'facts' in relation to their cancer also seemed to be reflected in the type of support they appreciated from their partners. Conversely, a young woman lamented her partner being unable to sense the subtle emotional attunement she needed. As she perceived it, he left at the time of her greatest need, because he felt unable to 'do' anything to make it better.

OLI: [Male] She's very, like – 'well...what can we do to fix it? You like.. when you go and get your hair done. Maybe we can go and get your hair done. (...) And if I'm like "nah I don't want to" she'll be like 'oh that's fine...let's watch Netflix...why don't we order a takeaway...you know she'll be doing..she'll just.. *help*. If I need...if I'm down about it. It's not *often*...I have to say. It isn't that often. But when I am.. down about it she'll be just comforting...and almost...whatever I wanna *do* ...like, whatever I like to feel better, I don't know.

SASHA: [Female] they [boyfriend] didn't know what to do...they knew they couldn't be of...well they didn't *feel* they could be of tangible help...so he saw everyone taking such amazing care of me and stepping up and so he thought.."oh..well it's ok...I'm not needed".

Romantic relationships were also characterised by having lineal and progressive 'stages'. How the cancer experience influenced the romantic relationship and vice versa seemed to be influenced by the perceived 'stage' of the relationship. For one young person, being a 'girlfriend' to a 'boyfriend' was associated with excitement and fun. She wasn't willing to disclose certain vulnerable parts of herself to him, seemingly not trusting that the relationship

would survive if she did. Later, she credits the survival of the relationship on having *not* shared these challenging parts.

CAROLINE: I wouldn't talk to him about it but I'd talk to my parents...it was such an early relationship as well...I think.. if he was my husband or something it would be different.. but I still wanted to keep him as my boyfriend, someone that, like, found exciting and um..wanted to do fun things with...'cause he wanted to come along to chemotherapy and I really didn't want him to come...it's 'cause I didn't know how each one would go... and I didn't want him to see what I was going through either.

This distinction also extended to actions or roles taken within the relationship. For example, women saw the role of 'carer' and 'boyfriend' to be mutually exclusive.

ZOE: Yeah..he was a bit more like a carer than a boyfriend.

Young people talked about the potential for their cancer experience to affect the progression of their romantic relationship to future 'stages', such as having children or getting married, which gave them more of a sense of an uncertain future. For heterosexual young people, compromised fertility was cited as an issue, whilst the homosexual young person mentioned the potential delay to adoption procedures.

LEE: I'm in a...same sex relationship...we want to adopt. And now with me having cancer..we can't adopt until five years clear, for example. But whereas, if I didn't have cancer I could start the process tomorrow, I now need to wait a bit longer.

Young people had certain expectations of their romantic partner. It was important for them to show commitment and longevity throughout the entirety of the cancer experience; showing short term or intermittent support was not acceptable. This also marked it out as a special relationship and different from friendship.

SASHA: There was a certain level of behaviour that I expected at that point..[and] (...) it was unimpressive and not good enough...he initially wanted to step up...but because his work is so higher on his priorities this wasn't a constant effort...it wasn't something that he was capable of constantly maintaining and keeping up.

It was extremely re-assuring to young people when a partner did show their commitment, demonstrating the importance of the romantic relationship.

ZOE: So he was like "no. I'm not going anywhere..I'm not going anywhere". So that gave me quite a lot of confidence..in the fact that he'd said and he kind of..he doesn't go back on his word sort of thing...so I was like..he said he won't so he's not going to.

SAM: I think she was getting quite stressed because...of the long term picture...like she didn't know whether (...) she felt like she could commit to it..if that makes sense...so I felt like...having those sorts of conversations...aren't very easy..but I felt like it was very..in the long term..a very good thing.

3.5. Theme 2: Challenge and Change

The second theme relates to the challenges and changes faced by young people and their romantic partners. By changing the roles played within it, cancer has the potential to rock the foundations on which the relationship was built, and emotions can intensify. Young people described the impact of this challenge and change, and how they found new ways of managing. Although not a separate subtheme in itself, transcending both subthemes was the need for new forms of communication.

3.5.1. Subtheme 1: New Parameters and Different Roles

Cancer challenges the basic parameters of a romantic relationship (e.g. reciprocity of care).

SASHA: [telling them about the diagnosis] was also the point at which I'd

break to them [boyfriend] that I won't be able to *be* responsible for them for the next six..nine..however many months...and they kind of..they can't *turn* to me with their emotional burdens at that point.

Although parents took on the bulk of the caring responsibilities, young people's partners took on some responsibility for their physical and practical needs. These ranged from taking financial responsibility when one was unable to work, undertaking practical tasks such as washing or dressing, and helping them cope with the side effects of their cancer treatment. Some young people feared that their partners perceived them in a different way as a result of their new responsibilities. They worried that being in a vulnerable, dependent position would lead to being a burden, or no longer being loved.

ZOE: I thought he was going to leave me to be fair...well I told him to a few times actually..because obviously I cared about him and I didn't want him to end up resenting me or hating me because of it.

Some differences between men and women were observed. For example, most women described their male partner as taking on a 'carer' role, but the heterosexual men in relationships with women didn't refer to this term at all. Females showed guilt and embarrassment about their male partners taking on physical duties, feeling that this was not something that their partner would naturally want to be doing, and lamenting the loss of 'feminine mystery' that ensued. They found the experience demoralising and uncomfortable, and there was an assumption that being seen in a certain way 'as a girl' was important for maintaining a healthy relationship.

ZOE: Well just actually being a *girl*...I wished I wasn't a woman (...) John was (...) sometimes even having to take me to the toilet, or change my sanitary pad (makes facial gesture)...which was disgusting on occasion. But yeah...because I couldn't bend over...It was horrible! (small laugh) I felt so...oh I don't know what it was...like...it definitely affected our relationship...like I don't want to start talking sex here but like it definitely affected that a little bit...once you've wiped somebody's bum and had to

shower them (...)it's quite demoralising...cause obviously he didn't *want* to do it.

CAROLINE: He was just holding back my hair whilst I was just throwing up in the toilet ... I felt ill..awful...I was like, I'm so sorry you had to do that, you know. Ha! He looked after me...ha! He tried his best! (laugh)

CAROLINE: Ben popped into my room when I was getting dressed...cause I'd lost a bit of eyebrow as well (...) and it was like "ah – ah – you know...personal...you know...don't wanna get, don't wanna *show* any of that".

HANNAH: He was amazing through it..but then I think..after the treatment the relationship just wasn't the same....like he'd seen me go through too much. And he couldn't look at me in the same way.

For one young couple, however, the 'carer' role brought a new intimacy, and the start of their sexual relationship.

CAROLINE: the only reason he started sleeping with me 'cause I was so poorly in the night and that's when my pain was sometimes worse so he'd get up to get me a drink or something like that so that that's how our physical relationship I think developed. Just being by my side with.. holding my hair back whilst I was throwing up..and..ueggrh!

Young people also took on new roles *as a couple*, for example, as 'battlers of cancer'. This caused difficulties in survivorship, as couples struggled to find their path as a couple without this joint purpose. The increased intimacy also meant that an inevitable break up could be delayed.

ZOE: We'd sort of got into the mental state of just being sort of 'co-getting through this' basically..so we had to sort of find out what was going on after that

OLI: I think we'd stayed together for that long..*because* we'd been

through it together. So because we'd been through the fight that I'd had with chemo..and cancer..and we'd *got over* that..*no-one* our age has done that...maybe 2 years we just kind of stayed together..because it was like "no-one else has done this, like, we've done this together", and so we feel super comfortable

3.5.2. Subtheme 2: Intensification and Amplification

The cancer experience appeared to intensify relationship experiences and their emotional consequences, both positive and negative. Actions were more likely to take on special meaning, and young people often had greater needs within their romantic relationships (e.g. more commitment from their partners). The experience was also associated with increased worry about their partner and fear for the future.

MEL: When you're going through something like that everything gets amplified...if I was in a normal situation I would probably have just brushed it off erm.. but as I was going through quite a difficult time it was amplified a lot

SASHA: As I was going through it I was kind of thinking well..the point is that whatever goes down in these months..they're kind of...they're things that always be in the back of mind in the memory..and things that will never be forgotten...it wasn't a standard 3 weeks in February it was...my 3rd and 4th or my 4th and 5th rounds of chemo.

Most young people did not mention worries about the future at all, citing the importance of constant 'positivity' as vitally important to their wellbeing. However being in a romantic relationship in the context of cancer brought some feelings of responsibility towards a partner and fear and worry about the future. The young person who had significantly reduced life expectancy after a relapse and the development of a secondary cancer was the only one to cite serious worries about the future, and these were related to his partner.

SAM: I definitely can see myself being with Laura for like..however long down the line..so the two main things that I worry about now..like

specifically is that having kids would be..I probably would be infertile...so like then you get on with like IVF..which isn't easy...the second thing I worry about is...I don't...it's not something that I'm constantly thinking about...but...it's not something I worry about for myself....but I worry about her.....it's like..if..like...I end up dying early..like prematurely.

The experience of a stressor such as cancer also puts relationships under pressure, bringing existing relationship dynamics to the fore.

SASHA: I feel like I took a lot of his...and carried a lot of his shit for him...for a long time [before cancer] without him being fully aware of that fact..and I think that then he sort of..then he was suddenly there without people [me] to...carry his shit for him..and then it became heavy again...so then it was the realisation that I'm giving so much priority and thought to this person who in many ways...gives so little back.

Going through an intense experience together had a profound impact on young couples, whether or not they remained together, and a special bond that the young people doubted they would be able to find again.

HANNAH: I don't think I'd be in another relationship where, kind of (...) I don't think I'd ever kind of have that bond with someone again. Cause it's a big thing, to go through together, so..yeah..I think maybe it was just a one time thing.

Young people sought more assurances of trust and commitment from their partners, alluding to the potential for them or their partner to be hurt. This need for more commitment seemed to show the relative importance and vulnerability of the romantic relationship; no-one described testing the commitment of their parents or friends. For some, the potential for intense emotional pain led to some young people to want to 'test' their partners love and commitment by pushing them away, or by encouraging open communication earlier on in order to prevent hurt later on.

ZOE: I thought he was going to leave me to be fair...well I told him to a few times actually (...) I was in hospital and shut the door and locked it...from the inside...and wouldn't let him come in! And told him that he should go home..and not think about me ever again.

SAM: At the point where it was like..we are either going to 'commit' to this, sort of thing..I felt like I needed to be quite open about everything...if either of us want this to be a long term thing, it means we need to talk about, the potential for what would happen down the line..and..just put everything on the table...I felt like...if you don't do that then you realise [intake of breath] I dunno let's say 9 months down the line and then you're much more invested in it...and then it's gonna be a much harder hit.

3.5.3. Transparent Communication

In the context of altered 'roles', and intensification of emotion, new challenges with communication arose. Whilst actions were cited as very important in showing support, in the midst of difficult experiences and distressing emotions, the need for openness about distressing thoughts and feelings became apparent. Some found this difficult and avoided it, but couples who managed to negotiate these changing communication needs enjoyed greater trust and connection.

ZOE: The other night I came in and I just literally put my jammers on and went straight in bed. And it was like hiding from the world. And then...John came back and it was like 'night' and I just kind of went [gestures rolling eyes] turned over...which I don't wanna get back into the rut of.

SASHA: Initially it [boyfriend] was sort of present...and then..he went on holiday for three weeks..and...he decided to take a break from life type of thing. Which included me. And..I didn't...he wasn't really *aware* that he was taking this break until after he's taken it..so..he didn't really let me know..and so things weren't talked out.

SAM: Having those sorts of conversations...aren't very easy..but I felt like it was very..in the long term...a very good thing..'cause we're on the same page. They weren't nice conversations but the outcome was like, really nice, like positive.

Young women were more likely to talk about the difficulties their boyfriends had with talking about distress and worry, whereas young men were likely to find female partners more emotionally attuned, and able to facilitate a conversation that helped them both overcome distress. The need to care for their partners emotionally was also important.

CAROLINE: I think that he thought that he understood everything, but...I knew he didn't. Like throughout a lot of the time he said "you're gonna be fine...you're gonna be fine..." I think that was his kind of his mechanism of coping with me being ill as well...it did irritate me...'cause I did have...I did have like: "you're really rubbish! And I *don't* think, chemo next week is gonna go that well".

HANNAH: I don't know if he actually could *talk* to me about being ill..'cause..like there were *times* when I had my check-ups, and I'd be like "ooh I've got my check-up I'm so worried!" And he'd never kind of res-like if we were texting he'd never respond to it?

SAM (male): Just having someone there...like checking in...like coming to see you..in a kind of..I dunno..like 'get's you'... sort of, whereas [small sigh] I feel like...with the boys like my mates.. it'll be: "how're you doing?".. "yeah I'm alright"... that's fine..sometimes. And then it's like "case closed, he's doing okay" sort of..that sort of check-in rather than actually explore how're you feeling about this or about that...like having more...like *actually* check you're okay..sort of conversation..and discuss stuff..check that she's okay as well cos it's not very nice to see someone you care about..in a bed..with no hair.

When communication went well, it prompted opportunities for a stronger relationship based on mutual trust. This young person describes the aftermath

of conversations about their future commitment to each other in the midst of his probable premature death.

SAM: I felt like it was very...in the long term...a very good thing...’cause we’re on the same page...they weren’t nice conversations but the outcome was like, really nice...like positive.

3.6. Theme 3: Managing Others’ Perceptions

Many young people thought people viewed them differently because they had cancer, including romantic partners and potential romantic partners. This was often a source of distress, and they employed a variety of approaches to cope, often by trying to manage conversations and *stories* about their specific cancer experience and cancer in general. Young people worried that changes to the way they looked or the way their bodies worked would change their relationship or change people’s perceptions of them as suitable romantic relationship partners.

MEL: People don’t know how to deal with it...people don’t know how to speak to you...they don’t know how to act around you. Which the first thing I said to everyone was: “I’m still me. I might have no hair...I might have a PICC line³ hanging out my arm...I might be dripped up every 2 weeks....but at the end of it...I’m still the Mel everyone has grown up with or...been out with or...whatever else”.

3.6.1. Subtheme 1: Fighting the Illness Identity: “I’m still me”

For one young person, she felt the way that her boyfriend viewed her during the cancer experience had changed. After being very protective of her when she was ill, he then distanced himself as she got physically better, rejecting sex with her before eventually meeting someone else and ending the relationship. This young person’s experience seems indicative of the way that a couple may struggle with the changing ‘identities’ they hold over the course of the cancer

³ Long, thin tube inserted into a vein to administer drugs (e.g. chemotherapy) intravenously

experience. The partner of this young person seemed confused about his role in relation to his perception of his partners changing 'identity'.

HANNAH: When I was in critical care..he came in and he would like hold my hand..like every day..he would kiss me...like he didn't show any signs that he was going *anywhere*...if anything he got like really *protective* over me? (...) And yeah...I don't know...he didn't give me any kind of inkling..I think..I just got in my own head that it was because my looks had changed and things..but I never really spoke to him about it. like..when we broke up he told me it was because he didn't want a relationship anymore.

Dating new people was particularly challenging for young people, who often struggled with knowing when to reveal their cancer history.

ADAM: People [dates] always clam up around cancer...when you can feel it coming up in conversation you're kind of feel like "oh gosh..."

Young people also mentioned being viewed in extreme ways by potential partners:

BECKY: A lot of boys think of it as something disgusting that I've had...but then...on the other hand there was guys who that used to say "oh my God..that is amazing!" type thing..and it would attract them more I think. But it's hard to find those type of guys. Because a lot of guys obviously think: "urgh..she's had cancer...oh it might be – be infectious or something like that".

Either as weak and broken...

ADAM: People [dates] sort of look at you as if you're a little bit..you know *weak* and..you know...broken?

...Or *more* sexually attractive:

SAM: This is gonna sound either very cocky or very stupid..but girls definitely reacted differently to me after they knew about the diagnosis. Which I found a bit weird. So they were kind of..I felt like they were more...I felt like I got more attention afterwards..which I found bizarre.

One young person imagined that the increased interest might be related to women feeling sorry for him, which made him feel uneasy.

SAM: I definitely felt like parts of it was people like feeling sorry for me...yeah. So..didn't feel great about it, really...it just made me feel a bit...uneasy.

One young person described the process of coping with dating partners' reactions. The way he described it seemed akin to putting on a suit of armour (getting his 'personality') and going into battle, dazzling them with a new perspective.

ADAM: When you *tell* people about it...especially on first dates and stuff...they sort of clam up and go: "Ah! God that's so serious" and I have to sort of...get my personality and be like "nope! It's absolutely fine! Ask...*any* question you want..and..I'm really open about it" and..sort of trying to get *over* the barrier first?

Young people were concerned about when and how to tell dating partners about their cancer history. Many felt a need to disclose it early on, either before meeting them (if online dating) or during their first date. Young people developed different strategies to try and manage unwanted reactions, which were often described as awkwardness, shock or pity. One young person described how she coped with having a visibly different body by wearing tops which put her scars on show. Rather than taking on the responsibility for deciding when to tell someone, this prompted others to ask, and prepared them for a potentially difficult story.

HANNAH: I think it's just so...so people *know* that they're there [scars]. Like..I used to keep them hidden all the time, and then part of me was really worried about when people saw them, like "what would they think?"

whereas *now*, it's a bit like, I'll just let people *see* them, and they can *ask* me what they're from, if they want to. And like...at least it's not a *shock* that they're there...people are gonna know that *something's* happened...whatever that may be.

Interestingly, three female young people mentioned that their mothers had advised that they did not tell potential dates about their cancer history, suggesting different generational preferences for privacy, or a greater fear about the consequences of disclosure. Young people felt unusually compelled to ignore their advice, even though they were often apprehensive about telling them, as it was vitally important but very sensitive information. One woman managed this by choosing not to tell online dating partners until she met them in person.

MEL: You get the odd one who it's "ooh..we'll meet up", and then it doesn't happen. So you think 'I'm glad I haven't told you anything'.

Telling dating partners early on in the relationship seemed important because it seemed the cancer experience had become a fundamental part of their identity; important for others to know if they were to understand them, and a way of understanding their dating partner, by gauging their reaction.

HANNAH: If they can't..I'd rather tell them and if they can't handle it like, *don't* get involved in my life? Not, like..you meet someone, really like them and then me tell them...and then be like "actually...this is too much...this changes the way that I see you...let's kind of...not see each other again?"

BECKY: My Mum always said..don't say anything..but I do now...cause I've usually got a few drinks in me and it just comes out anyway! So I just go: "so yeah..that's me! Take me as I am or..[gestures with thumb] out on the road!"

MEL: If it became a long term relationship...if..touch wood.. something did happen and I ended up ill for whatever reason...would they be able to

stand by me? Which obviously would be a massive thing for anyone. Erm.. so I think that's what kinda made me a bit reluctant at first [to tell dating partners]...cause everyone's different you don't know how anyone takes anything..so it's a bit of a funny situation.

Some young people felt that people would choose not to date them because of the hereditary nature of cancer, or the potential impact on their fertility.

MEL "Cause the first thing you think of is 'could it be hereditary?' if you obviously don't know about what type or you know what time but you don't know anything about it. Erm so that could kind of be a bit of a 'hang on a minute..you're aright I'll pass".

3.6.2. Subtheme 2: Physical Intimacy and Sexual Attractiveness

Cancer and its treatment causes change to bodies, which can affect young people's relationships with them and their experience of sexual intimacy. Young people were often concerned about how their bodies were viewed by romantic or sexual partners. Young women often alluded to changes to their bodies making them less sexually attractive to their partners.

HANNAH: I remember instigating and he couldn't..he shrugged me off? He couldn't..even touch me? And it's like...oh okay...and then *that* was kind of the first sign that something was really really wrong. But in my head...I'd blamed that on the fact that I looked so different..and that I had the scars, and all of that..and then, like, for *ages* I was absolutely terrified of being intimate with someone again.

During the intense treatment phase, most young people lost interest in sex at all, and afterwards, most observed changes to their experience of sexual intimacy in some form or another. For one, having a committed romantic relationship which didn't involve sex became more important than having casual sex with multiple partners. For others (mainly women) they were less likely to want sex due to reduced body confidence, particularly in the context of their partner taking on 'caring' responsibilities. Changes to sexual functioning or physical impairment caused some to worry that sex might not be as good for

their partners. The following quotes also reveal different assumptions about what their sexual partners value in a sexual encounter.

SAM: [Male] "Given...it'd be her first time [having sex] I then stre – well I don't stress about it...I worry that then it would kind of like...I don't want it to be...like shit for her...because I can't..I don't know what might happen basically...yeah. I kind of like, think about that.

ZOE: [Female] Obviously physically wise...I can't move as well as I used to? (...) If I'm in a certain position I'll be in pain..so we had to basically modify everything we did...for me...if you know what I mean. So at the begin- at first it [sex] was quite like..not like rigid..but awkward?

Relationship 'success' was related to having an 'ideal body', which also led to greater confidence. Changes to the body through cancer mean that you are less likely to have 'success' in terms of romantic and sexual relationships.

BECKY: [Female] I think because...obviously at 16 I had no hair..I was fat..and then I started doing, like, slimming world, and watching my weight...and watching what I was eating...experimenting with make-up and stuff like that...and then obviously when it comes to the point where you've lost that weight and you've got nice hair you feel like a normal teenager you feel like you've caught up with the world...that's what gave me my confidence back really...and then I met Lee [boyfriend].

ADAM: [Male] Had I..not had that experience [of cancer] and perhaps I'd grown tall and lost weight and become slim and gone into university that life with different influences I suppose to be crass about it..I've not...I've never had the 'shagging around at uni' sort of phase? I've always gone in to, you know, relationships and sort of...any one night stands that I've had have been sort of with people I knew..and just sort of awkward.

Despite partner's assurances that they still found them sexually attractive, young people's feelings about their bodies seemed to be influenced by internalised discourses about what constitutes the 'ideal' sexual body.

ZOE: Because it was hard work me showering and stuff I didn't do it as much as I would have liked to...if you know what I mean. So obviously I'd felt like he didn't find me attractive any more. Which I'd been *told* on numerous occasions isn't the case...but obviously that was how I *felt*.

A changed body was also seen by partners as a sign of strength, leading to new feelings of pride and admiration.

CAROLINE: I was feeling a bit better, a bit like "oh God I've got a buzz cut and I've had such long hair beforehand"...but he said look I love you for who you are not cos of what you look like. I think he was sort of proud that I went through all that".

3.7. THEME 4: Different 'Selves' and New Perspectives

Many people thought that the cancer experience had brought a change in their personality, which in turn affected their approach to their romantic relationships. Young people sometimes felt that they looked for different qualities in a partner, whilst those in existing relationships questioned whether or not they were still compatible. Young people felt that their cancer experience had resulted in different priorities in relationships; some had more appreciation of their unique needs and values as they continued with current relationships or entered new ones. For some, this was associated with a rejection of what was 'expected' in terms of social norms.

The changes reported by young people were varied and complex; reflective of the multilayered impact of the cancer on their lives. For some, their sense of themselves changed so much that they described themselves as two different people pre- and post-cancer, even if people close to them thought they hadn't changed. One described the long process of learning to accept her 'post-cancer' self.

HANNAH: It had changed me so much like with my looks and things, and I felt like I looked like a completely different *person*...but I think...I kind of

put the person that I was before I was ill on a pedestal? And I always wanted to *be* that person again for such a long time...and I hated the fact that I looked different..and that my personality was totally different as well..and it took me a *long time*, to kind of accept that I was a different person..but that's not necessarily..a bad thing?

Most described their cancer experience as having a largely positive impact on their personality, citing a new drive to achieve the things they wanted in life, an increased sense of responsibility, and a greater awareness of their potential. But some young people felt the cancer had also left them feeling somewhat jaded.

ZOE: I used to be very happy, chippy about everything and now I'm a bit more pessimistic than optimistic...which I've noticed...and John's definitely noticed... so..yeah that's something that I'd like to get back at some point. But that's just how it is at the minute (...) we're definitely not like..young and free and easy sort of mentality that we were back then.

Such was the impact of the cancer on this young couple that it seemed the cancer could be described as a 'couple's disease'. The changes they had both experienced as a result of one person's illness resulted in an increased caution as they contemplated the future of their relationship.

ZOE: We are seeing how things go..as we've said sort of like a *new* relationship again cause we're both very different after having cancer...we're still trying to get back to what we were before cancer which we decided a few weeks ago it's probably never going to happen...so we sort of see if we like each other like this!

Some felt that they were now more emotionally robust and resilient; better equipped to cope with the potential pain that might come with a future romantic relationship. However they also described themselves as more emotionally sensitive, and with a greater capacity for making meaningful connection.

HANNAH: Going through what I have has made me quite thick skinned..because..like I just kind of thought [when partner broke up with her] well..if that's what you feel, then, that's, like I can't *make* you...I can't *force* you ...I'll just get on with my life...life goes on...I think..if I can get through what I've been through *now* then a break up's not..it's not a big deal!

HANNAH: I think it's more like..I don't get..as worked up about things that I would have done before..I'm actually quite laid back now (...) but I think I'm also lot more sensitive in a lot of ways, as well

SASHA: I've been able to connect with less *barriers*...I don't think twice now if I haven't received a reply from someone a couple of times (...) I don't mind writing again..expressing great amounts of love..without *needing* something back from it...I know that it's there from my side and that that can be shown and...it's one of the most important things.

SAM: So...we haven't had sex...I think it's been quite refreshing because in the past...the first I would do is have sex with someone and see where that goes...if it was to go anywhere...whereas now it's like...it's really nice..because..[I] got to know her...and know that I...really like her.

The experience of surviving cancer gave young people new understandings about their own worth and value, which was linked to greater confidence in relationships.

SASHA: You are the only thing you have to offer...what makes you different is the only thing thing that you can teach other people. Because everything else they can learn from everyone else...and that's the only thing that you as a life have any call for..so you might as well do that...and share that..and like...teach that...(...) me being myself is the thing that..the *only* thing that the world could have possibly missed if I wasn't there...Everything..everything else goes on...but the bit of me that is only me...that's the valuable thing. And that's the thing that I think we

tend to judge ourselves on the most...and that's the last thing to do!
Because it's..yeah..best part of you.

This led to young people becoming more outgoing and adventurous with their romantic relationships, taking risks that they would not have taken before.

ADAM: I think it [cancer] sort of defines me quite a little bit. You know, being outgoing and diving in to relationships with people it's just sort of something I...sort of...quite proud of! So..literally I think it's (...) it was the best thing that ever happened to me! The best experience that I could have had because it was really defining for me so yeah – definitely changed my personality and for the positive.

Young people described more clarity and focus in their approach to relationships, and a new awareness of what they wanted; making the most of their time was more important, and romantic relationships were a key part of this. Despite this, young people commonly described not feeling too preoccupied with actively seeking a relationship.

SASHA: I'm in the state of mind where (...) I'm not looking forward so much...I'm...more in the present...and not trying to define where I am or what I'm doing...I'm sort of letting things that happen happen..and trying to actively sort of go about putting in things to my life that might be helpful like...creativity or..that kind of thing.

The experience of serious illness led to young people feeling that they were more mature, and to seek a relationship with a more emotionally mature partner.

HANNAH: I think...that they [future partners] would have to be quite good with their emotions? Like..I don't think I'd be able..like with Tim..when I told him about that I was worried about my review meetings and things...and he wouldn't really respond to me? Like I'd need someone who could probably be a little bit of a crutch..in a way? And not be like "oh that's okay"..cause obviously when it comes to having children and

things as well...I mean...If they can't even have a conversation with me about what happened or...how I'm worrying about my appointments then how are they gonna have conversations like that if they have to?

SAM: I think probably it [new relationship] just wouldn't of happened...if I hadn't had got it [cancer] really..I probably would have been too immature..and like, I feel like I've changed a lot since I was first diagnosed...and I don't think our personalities would have been that compatible had I..just...remained on the same trajectory as I was on...which is...I do think it's weird..it does make me think..but I'm ok with it because it's not like...I know that I'm not saying.."we're together because I'm ill"..I'm saying: "we're together because I am more mature now than I would have been....so that's how I think about it I think.

Cancer often led to a readjusting of priorities:

SASHA: It was the realisation that I'm giving so much priority and thought to this person who in many ways..gives so little back. Whereas there are these incredible people around me who I could give my priority and thought to instead. And..If I transpose the energy that I've put..in to this person...

Many young people described a new sense of awakening and increased drive to achieve their goals and dreams following their cancer experience. One young person described it as no longer being 'on autopilot'. For him, the change in his relationship approach developed when he was diagnosed with a second rare cancer which was likely to reduce his life expectancy.

SAM: That certainly was the kick in..that made me sort of...really start thinking... because when you're told that it's not just "you've got 95% cure rate..you're cured..you're in remission from your Hodgkin's" it's "you've got this..which you need to be monitored for every three months...you've got a 10% chance in the first year that you're gonna get multiple myeloma"...that's when you start thinking, like 'shit...what am I doing..what do I actually want?'

Other young people found that the experience had led to a more defined sense of self, and an interest in their own unique needs. They tended to care less about adhering to expected social norms in terms of romantic relationships and were no longer as preoccupied with what their peers thought about them.

SASHA: I'm really not worried about what people think? (...) So I don't know if I was *paranoid* about people's thoughts before...but now they seem to be more positive (...) I'm not *apologising* for being myself? And therefore, if I don't...if I don't doubt myself then there's not much reason for other people to doubt me.

SAM: Now it's kind of like..I don't actually have to do that...which sounds very stupid, because obviously you don't *have* to do that but you get..sort of group mentality makes you think 'yeah..it's a Wednesday' (...) where as now it's kind of like..'I don't actually have to do that. I'm going to stay at home or like, go out for dinner or whatever'. I would never have thought like this then [before cancer].

Related to reduced worry about others' perceptions was the loosening of gendered 'norms', including how young men and women were expected to perform in terms of their romantic and sexual relationships. For one young man, his cancer experience led to the realisation that he wanted a committed romantic relationship rather than lots of casual sex. Similarly, a woman found that she was no longer willing to 'eliminate' her expectations of her male partner and expected more effort and commitment.

SASHA: [Female] Because on some level...when everything was going ok I was ok with it being only friendship...but..when things aren't ok then..yeah..you don't monitor your expectations anymore and kind of the base level comes out...and that's the part that needs to be respected...I don't have much interest in sort of...at the moment and sort of...fooling around on sort of...sex level.

SAM: [Male] For me personally it make me think...right...there is a potential that there is a significantly reduced cap on like how long you're gonna live...so..you wanna make sure that you're making the most of that time..you're doing what you wanna do...you're achieving what you wanna achieve..rather than sort of meandering through...it just makes you think: 'Am I doing what I wanna do...what do I wanna do...and who do I wanna do it with?'

4. DISCUSSION

4.1. Overview

In this chapter, the key findings are summarised and considered in relation to the research questions and the relevant literature. Following this, the implications of the findings will be outlined. Lastly, a critical evaluation of the study and final reflections are presented. In line with my critical realist position, I recognize that any theoretical links I make to the data are one potential way of thinking, rather than being a claim to 'truth'.

4.2. Summary of Findings

The aim of this study was to consider the impact of cancer on the romantic relationships of young people entering adulthood. Four main themes and seven subthemes were constructed through analysis of the data.

The first theme was 'construction of romantic relationships in context'. Cancer can highlight and may change how romantic relationships are conceptualised. They are differentiated from other types of relationships (e.g. friendships) by having progressive stages and higher expectations, which often become more visible during the cancer experience. Having cancer may also highlight and increase a sense of ambivalence about separating from parents towards a romantic relationship, a 'typical' developmental sequence in Western culture. The second theme was 'challenge and change'. Romantic partners can be an important 'strength' for young people, but cancer brings changes to roles within relationships, challenging the foundations on which the relationship was built which can lead to more uncertainty about the future. Emotions within relationships are intensified and new 'relationship skills' are required, such as more open communication about potentially distressing issues. The third theme was 'managing others' perceptions'. Young people often feel that romantic partners or potential romantic partners perceive them differently (often as less attractive) because of their cancer, which can lead to feelings of

disempowerment, frustration, and loss of confidence. The fourth and final theme was 'different 'selves' and new perspectives'. If the emotions of cancer are managed well (e.g. reflected upon) the experience can bring increased satisfaction in romantic relationships. Existing couples can enjoy a sense of increased trust and connection, whilst a new focus on priorities can lead to more fulfillment in new relationships, via a greater understanding of 'self' and less concern over others' perceptions.

There was some interconnection between the themes and subthemes (see Appendix O for a visual representation). Romantic relationships in early adulthood were conceptualised as having a limited range of roles available to them; which is linked to the pressure on changing roles in the context of cancer. The changing perceptions of romantic partners is part of the 'challenge and change' of cancer. Furthermore, navigating the challenges of cancer in the context of romantic relationships can contribute directly towards the development of 'different selves' and new perspectives towards romantic relationships.

4.3. Returning to the Research Questions

Three research questions were developed to guide the exploration of young people's romantic relationships in the context of cancer. The first asked how the romantic and sexual relationships of young people entering adulthood are affected by cancer; the second how young single people are affected differently from those in relationships, and the third how young males and females might be affected differently by their experience. Below, the findings are considered and discussed in relation to these and to the existing AYA literature, before reflecting on broader points of interest arising from this initial discussion.

4.4. Discussion of Findings in Relation to Existing Literature

Similarly to Carpentier & Fortenbury (2010) and Carpentier et al. (2011), young people report that being in a high quality romantic relationship greatly enhances their recovery and psychological wellbeing, a finding also present in the wider adult literature (Manne, Badr, & Kashy, 2012). As a 'strength' and 'someone to

talk to', a romantic partner helped facilitate a continued sense of normality and appeared to be important in bridging the gap between parental relationships and friendships in the cancer context.

However, similarly to Robertson et al. (2016) and Robinson et al. (2014), the results indicated that cancer brings new needs and changes to existing romantic relationships which can put them under strain. Although parents tend to take on the bulk of caring responsibilities, young people and their partners were sometimes required to adopt unfamiliar roles in relation to each other (e.g. 'carer' and 'cared for') which are more typically associated with much older adults in mature relationships.

Whilst older married couples might have a wider range of roles available ('in sickness and in health'), the range of roles available within the construct of 'boyfriend' and 'girlfriend' may be fairly limited, and perhaps unsuited to the flexibility required in the context of cancer. One young person demonstrated this by explaining that she wanted to keep her partner as 'fun' and 'exciting'; which necessitated separating him from the reality of her cancer experience. In the context of a turbulent developmental period, lacking the flexibility to adapt to the roles of 'carer' or 'cared for' may be particularly challenging, risking relationship breakdown and further psychological distress.

In this sample, young people with male partners (heterosexual women and a gay man) were more likely than heterosexual men to describe their partner taking on caring responsibilities. Underlying the descriptions of women were certain gendered stereotypes, including implicit (and sometimes explicit) assumptions that their male partners were not 'natural' carers. They were often surprised, or even amused by their partners' caring actions; implying that they were going beyond what was expected (Caroline: 'He looked after me - he tried his best – haha!'). They also seemed uncomfortable about being 'cared for' by their male partners, with intimate physical functions being intrinsically unfeminine and ideally hidden from view.

In addition to not being physically cared for by their partners, heterosexual men were also more likely to avoid being cared for by their parents; seemingly more

invested in retaining a sense of independence. They often implied this was no different to how they were before cancer (Sam: 'I'm not very good with contact...which upsets my Mum'). Although avoidance of being 'cared for' was most commonly reported by heterosexual men, most young people referred to worries about being burdensome to their partners or parents. Having only recently moved away from a position of childhood dependence, and with a developmental imperative to prove their independence (Kroger, Martinussen, & Marcia, 2010), young people may be more likely than older adults to try and cope alone, both physically and emotionally.

Relationship status and gender also intersected. The friends of young single men did not provide the same level of emotional support as those of single women, and they reported significant difficulty talking to male peers about the distress associated with their experience. Single young men were also less likely than single women to talk to their parents, who often spoke of their mothers as being a key source of support. For men, it seemed that their previously acceptable forms of communication (e.g. humour) were not sufficient or flexible enough to cope with the new type of communicative content necessitated by the cancer experience. In fact, forming a romantic relationship was cited as a particular relief for one young man, whose friends were unable to provide the nuanced emotional care that he needed. This supports the previous finding that young single men are at more risk of psychological distress than their partnered peers (Carpentier et al. 2011), and suggests that being part of a predominantly male peer group who are ill-equipped to talk about distressing emotions may be a particular risk factor.

Similarly to Carpentier & Fortenberry (2010) and Stinson et al. (2015), who found that reduced body confidence caused problems in relationships, some young people feared that their partners would perceive them as less desirable because of their new 'carer' or 'cared for' roles, and the changes to their body. Previous findings suggest that changes to sexual functioning can be a source of conflict in relationships (Robertson et al. 2016). Although many of the participants (male and female) described a loss in their sex drive whilst they were undergoing treatment, young people did not report this alone as having a major impact on their relationship. But feelings associated with loss of

attractiveness *were* cited as being an issue, particularly for women. Although partners tried to reassure that they still found them attractive, this usually did little to alter their feelings, suggesting that they were firmly held, subjective and more related to an internalised body ideal (White, 2002). This was also found in Freidus's (2017) study on male partners of breast cancer survivors under 50, who reported that their sexual attraction to their partners had not reduced, but their partner's lack of confidence meant less sexual contact. Poor body image may also contribute to a lack of intimacy and connection due to misunderstandings over a partner's emotional position.

As previously cited in the literature (e.g. Nieman et al., 2006; Russell, Galvin, Harper, & Clayman, 2016), both heterosexual men and women cited possible infertility as an issue for the future. Women in the current study were more likely to fear that their cancer history would delay them having children, and the young person who identified as gay feared that his cancer history would delay his planned adoption process. Heterosexual men were more likely to describe the single life (including casual sex) as a 'right of passage', and to feel that cancer may have prevented them from this.

In addition to the challenges cited about, experiencing cancer often fostered a special bond between existing couples which increased the likelihood of them staying together, or made breaking up more difficult. In line with Robinson et al. (2014) and Robertson et al's (2016) findings that cancer can strengthen relationships that are already strong or exacerbate conflict for those who are struggling, this study found that cancer can intensify emotions and amplify the meaning of relational actions within romantic relationships, bringing intensely pleasurable feelings of connectedness when trust is established, but also of pain when it is lost. This intensification of emotions also included fear of loss of the relationship itself and of being perceived differently by their partner (e.g. as 'burdensome'). Sometimes young people tried to push their partner away as a result, possibly as a means of gaining back a sense of control; to protect themselves from hurt further down the line, or as a way of 'testing' their commitment.

Young people's behaviours within relationships required adaptation. Whilst Stinson (2015) found that younger adolescents were less likely to start relationships because of their reduced contact with peers, some young adults in their 20s were unable to do the things they used to enjoy within relationships (such as physical exercise or drinking alcohol). Young people and their partners may also require new relationship 'skills'. There is a new need to communicate openly about sensitive, complex issues such as the implications for the future, and the emotional impact of the cancer. As Robinson et al. (2014) report, a lack of communication can lead to a loss of intimacy and problems in the relationship. Whilst these studies posit that a lack of communication around changing sexual desire can be problematic, the current study suggests other barriers to communication such as low mood, and new challenges in relation to future 'fantasies' as a couple (e.g. sharing a home, raising a family or travelling the world). Difficulties in communication are also reported in the general adult literature, which found that couples often have difficulty with communicating openly and tend to avoid raising cancer-related concerns with each other (Manne et al. 2006).

Young people may face particular challenges when single and dating. Similarly to the younger adolescents in Stinson et al's (2015) study, young people in their 20s also worried about how and when to tell dating partners about their cancer history. Young people often sought partners via online dating sites, where they frequently encountered awkwardness and unwanted sympathy when they disclosed their cancer history. Although Carpentier et al., (2011) and Hamilton & Zebrack (2011) found that young people may actively avoid relationships because of these concerns, the young people in this study were not put off altogether, even though it did make them apprehensive about how and when to disclose their cancer history in the future.

Despite several authors reporting negative reactions from dating partners when they learnt of the young person's cancer history, the current study was the first to suggest that that young people may also receive *more* sexual or romantic interest because of their cancer experience. This sometimes caused discomfort to young people, who were not clear about the reasons why. It may be that

increased notoriety amongst a peer group, perceived bravery and strength, or the evoking of caring responses from potential partners all played a part.

Break-ups during cancer can be very painful, partly because of the increased sense of vulnerability and disappointment at being let down in a time of increased need. However, with time and reflection, painful break-ups in the context of cancer can lead to greater confidence, and a new readiness for emotional connection. This relates to broader changes in approach to romantic relationships which can occur in cancer survivorship. Young people showed a greater awareness of 'self' and what they wanted from their future relationships, such as a different type of partner, more commitment or greater emotional support. They seemed less guided by societal or peer expectations, leading to opportunities for more fulfilling relationships.

This leads on from findings by Carpentier et al. (2011), who found that young people took relationships more seriously after cancer, and Robinson et al. (2014) who found that young people were likely to re-evaluate their life and change their priorities, either bringing couples closer together or hastening the end of conflictual relationships. Thompson et al. (2013) also found that young people who had experienced childhood cancer were more likely to seek partners who were more mature and able to cope with increased emotional need.

4.4.1. Who Was More Affected and Why?

Naturally, there were numerous individual differences in the way that young people's experience of romantic relationships were affected by their cancer. On viewing the data as a whole, however, tentative inferences can be drawn about the pattern in which these differences occurred.

Young people whose lives were put at greater risk (e.g. by a rarer cancer, a relapse and/or a second cancer) were more likely to feel that cancer had made a significant difference to their approach towards future relationships. Similarly, those with a more significant physical impairment after their cancer, and whose partners took on significant caring responsibilities (particularly involving intimate physical care) also reported a high degree of change to their existing

relationship, mainly in relation to the change of roles and perceptions as outlined above. It may be that the more caring responsibilities taken on by the partner, and the more intimate these are, the greater the level of impact on the relationship.

There also appeared to be factors relating to the quality of people's relationships which influenced how much their relationships were impacted. Out of the six who were in relationships at the time of their diagnosis, just two young people had stayed together with their partners *and* reported their relationships as 'strong' by the time of the interview. Interestingly, they were the only two people to describe feeling certain that their partners would be there for them during their diagnosis stage, not to fear that their partner's perception would change, nor to try and 'test' their partner's commitment. Tentatively, we might infer that the strength of the relationship, degree of trust in their partner and balance of power in the relationship may influence the likelihood that the relationship quality will remain high in cancer survivorship. Perhaps tellingly, however, in relation to the point above, partners had not taken on any significant caring responsibilities in either relationship.

Furthermore, young people who manage to communicate well about difficulties that arose during cancer may be more likely to enjoy a high quality relationship in the context of cancer. The young people who tackled difficult subjects together reported a strong relationship, whilst those who *avoided* communication reported troubles in their relationship.

Viewed through the lens of Brennan's (2001) social-cognitive transition model, these factors may give new insight into the potential mediating aspects involved in young people's process of adjustment, and how their mental models incorporate the cancer experience into their meaning-making about the world.

4.5. Theoretical Links: Issues of Interest Transcending Across Themes

4.5.1. Understanding Ambivalence and Confusion

Young people expressed ambivalence about wanting to be close to their parents and their romantic partners in the context of cancer. Understood

through the lens of Bowlby's (1960) attachment theory, the young people felt compelled to draw closer to primary attachment figures during a period of acute stress and uncertainty. However, ambivalence occurred when this instinct was counteracted by the equally compelling developmental urge to move away from their family of origin towards a new 'attachment object' in the form of a romantic relationship (Erikson, 1968; Marcia, 1980; Marcia, 1966; Carter & McGoldrick, 1999).

During periods of stress or threat, particular *styles* of attachment behaviour, learned in infancy, may be activated within a romantic relationship (Hazan & Shaver, 1987). Although these may be modified due to their increased cognitive and emotional capabilities in early adulthood, Crittenden (2005) argues that young people will usually aim to avoid or increase affect, depending on which was most effective in gaining their parents attention in infancy. When facing stress or potential separation from their partner, they may try to distance themselves (emotionally and physically) in an attempt to avoid affect, become more emotionally 'needy' in an attempt to illicit the extra care they need, or a combination of the two. One young person's description seemed to show an ambivalent attachment style (Ainsworth, Blehar, Waters & Wall, 1978), ostensibly seeking distance by asking their partner to leave, but also showing heightened emotion, demonstrating that they actually needed *more* care and attention.

4.5.2. 'Defences' and 'Post-traumatic Growth'

Young people often talked about the importance of their partners in helping them feel 'normal' and to cope by remaining 'positive'. This fits with the model of coping proposed by Miedema, Hamilton & Easly (2007), who suggested that perceptions of 'invincibility' and 'normalcy' were particularly important in helping young people survive the cancer experience psychologically.

Perhaps understandably, this 'positivity' was not limited to their internal worlds; young people described a range of techniques to ensure that people around them remained positive as well. Sometimes this meant using different language and encouraging others to do the same (one young person described his illness

as 'HL' rather than cancer), in the hope that this would reduce people's 'shock' response and disassociate it from any connotations with death.

In psychoanalytic terms, repression of distressing thoughts about cancer (e.g. as life threatening) may be thought of as healthy defence, protecting the young person against thoughts of dying young which are intolerable to the psyche (Freud, 1894; 1896). Whilst functional and adaptive for much of the time, 'repression' may no longer be useful in survivorship, when feelings of underlying sadness are finally 'allowed' to emerge (Grinyer, 2009).

Defences such as 'repression' may also become defunct if faced with a relapse or secondary cancer, as occurred for one young person in the study. He sought psychological support when a premature death became a more realistic possibility, and in the process of facing his distress, underwent significant psychological changes. These were specifically related to his approach towards relationships; he described having an increased capacity for meaningful connection and sought a different type of relationship which led to increased happiness and fulfillment. This supports a previous finding by Barakat, Alderfer, & Kazak (2005), who suggest that reducing avoidance strategies can increase the likelihood of 'post-traumatic growth' (Parkes, 1971; Frankl, 1963).

4.5.3. Perception and Identity

Crossing the majority of the themes was worry, fear and distress about how young people were *perceived* by others. This was an issue for those in existing relationships, particularly in relation to how their partner viewed them and their bodies, *and* for young people who were single and initiating new relationships after cancer. In relation to the latter, this may have been due to the anxiety experienced when they mentioned cancer; as a relatively rare disease in young adulthood, dating partners may be unused to hearing about it unless in very negative terms, and would be potentially ill-equipped to talk about serious illness.

They are also at risk of discrimination and stigma from potential romantic partners, which adds an extra burden to the emotional experience of dating.

Disclosing their cancer history risks reducing their desirability as a romantic partner, including a risk of a premature death, of potentially needing more care throughout their lifetime, being at risk of passing on a hereditary disease, or possible infertility. Developmentally, young people in adolescence and their early 20s gain a healthy sense of self through forming successful peer and romantic relationships (Erikson, 1968; Marcia, 1980; Arnett, 2000), so it is perhaps unsurprising that being positively perceived by peers and potential romantic partners is a major concern.

However, these factors may make it more likely that young people seek and find a partner who is less concerned with such aspects, and who may actively admire their emotional and physical resilience as a cancer survivor. Young people alluded to an inexorable need to tell dating partners very early on about their cancer history, despite their parents suggesting that they should not. It seemed that cancer had become an important part of their identity that was important for new partners to understand; gauging their responses early on gave young people important information about whether they wanted to continue dating.

4.5.4. Being 'Seen'

Within a close, intimate relationship, the physical brutality of cancer and the changes it wreaks on the body are laid bare, and I gained the sense that being 'seen' in this way by a romantic partner had particular meaning for female young people. Young women alluded to drastic consequences if 'seen' in an essentially non-sexual way, as if it was a boundary line not to be crossed. Either their partners had 'seen too much' and the relationship had ended, or the relationship had been saved by keeping them from 'seeing' physical changes.

There was a crucial difference between this expression of distress and the way that young men expressed their concerns about their bodies. Whilst young women were more likely to fear their relationship would change because they *were seen* in a different (implicitly non-sexual) way by their partner, young men were likely to fear that their partner would not enjoy sex as much if they were not able to get or maintain an erection. Both are suggestive of a powerful traditional gendered discourse in operation, with men as agentic and

responsible for sexual enjoyment and women as passive recipients of the male gaze (Mulvey, 1989).

4.5.6. Seeking Help

Similarly to Carpentier et al. (2011), this study appeared to show evidence of 'hegemonic masculinity' at work. This refers to the social processes pertaining to an idealised version of masculinity, including robustness and strength, suppression of needs and resistance of help-seeking (Mahalik et al. 2007; Gannon, Guerra-Blanco, Patel, & Abel, 2010). In the current study, young men generally reported having fewer people to talk to than females did. Not only did they seem less likely to seek support from their families, as also reported in the adult literature (Gray, Fitch, Phillips, Labrecque, & Fergus, 2000) but their peers seemed ill-equipped to know how to facilitate a conversation about the emotional distress of cancer.

This was shown also in the way they tended to talk about emotional difficulties (e.g. Sam: 'I was getting myself very frustrated'), either by minimising them, or even by blaming themselves (de Visser & McDonnell, 2013). Their responses offer some guidance about the type of psychological support young men might find helpful. One male in this study suggested that the type of psychological support he received (CBT) was very well suited to his sense of logic and practicality, which connects with the assurance young men in particular gained by acquiring knowledge about cancer or by having a practical solution. Within this framework, *knowing* there was 'nothing he could do', helped him to compartmentalise his worries and focus elsewhere. Another young man suggested that the long term talking therapy he had sought from a psychiatrist was not helping him anymore, and that he might find a more practical 'life coaching' more helpful. These findings echo Freidus' (2017) finding that male partners of breast cancer survivors solved their difficulties with 'logic', and the wider cancer literature which finds that males are much more likely to seek help by gathering information, and women through eliciting support and encouragement (Dale, Jatsch, Hughes, Pearce, & Meystre, 2004).

4.6. Implications for Clinical Practice and Provision of Support

Romantic and sexual relationships are a core part of young adulthood, and the findings have implications for all those interested in the psychological wellbeing of young people with cancer, including National Health Service (NHS) health care professionals (HCP) such as Clinical Psychologists and Clinical Nurse Specialists, and third sector providers such as the Teenage Cancer Trust and others dedicated to working with younger cancer survivors (e.g. Trekstock, CLIC Sergeant). The findings may also have relevance for family members, partners, and young people themselves.

4.6.1. Individual and Couple Level Approaches

Young people's romantic relationships are often challenged by the cancer experience. Robinson et al. (2014) reported that young people want support from healthcare providers to cope with the increased strain on their relationships, particularly those related to sexual and emotional intimacy. The findings from this study suggest that support in navigating changes to new 'roles' and in understanding fears about changing perceptions may also be beneficial. Psychological support could meaningfully focus on enhancing couples' ability to communicate with each other about distressing or uncomfortable aspects of their experience, such as the impact of the cancer on their future (including their fantasies and dreams about their relationship) or how low mood and anxiety could affect them as a couple.

As previously indicated, how and how much future or existing romantic relationship are affected may depend on the cancer prognosis, and the degree and nature of 'caring' responsibilities taken on (e.g. care related to 'intimate' physical areas). Relational aspects such as the ability to communicate well or the strength of the relationship prior to cancer may also have an effect on how well a couple is able to cope with the adaptations required. An awareness of these factors may help tailor individual support to young people and their partners as they navigate their cancer journey.

The study also highlighted a number of areas pertaining to 'post-traumatic growth' (Zamora et al., 2017). For the young people in this study, reflection and space to process what has happened to them seemed particularly instrumental

in allowing this to occur, and those who were able to come to terms with disturbance and change in their lives also described the most positive changes on their relationship approach. Helping young people to reflect on their experience through psychological therapy could be useful in scaffolding young people towards achieving such 'post-traumatic growth', which could benefit their current and future relationships. Facilitating a range of opportunities where this process could occur (with an individual therapist, in a psychotherapeutic group of young people) could be another area of focus.

The findings may offer some very broad guidance in how to tailor different support to young men and women. Whilst taking care not to generalise, young women may need particular help to think about how changes in perception by their partners may affect their confidence, whilst young men may need support in deconstructing organised constructs such as 'hegemonic masculinity' which might deter them from getting psychological help. Single young people who are dating after cancer might require extra support with talking to dating partners about their cancer history. Support via the Teenage Cancer Trust website (e.g. The Young Person's Guide to Cancer) offers some practical guidance on how to broach the subject, with specific reference to internet dating.

4.6.2. Wider Contextual Levels of Influence

Inspired by critical psychology approaches and Bronfenbrenner's (1979) model of human development, an ecological systems model posits that there are wider levels of influence which can affect an individual behaviour and experience and may be a useful framework by which to consider other possibilities for supporting young cancer survivors with their romantic and sexual relationships. Exploring change across wider levels of influence (e.g. community context, dominant discourses) could effect change at all levels of the system (DiClemente, Salazar, & Crosby, 2013).

Whilst 1-1 psychological therapy may be helpful for some, other young people might require a different sort of support, particularly young men, who may be less likely to seek this sort of 'professional' help. Young people have already voiced the need for help from people their own age (Palmer, Patterson, & Thompson, 2014; Treadgold & Kuperberg, 2010). Harnessing the collective

and creative thinking power of young people via community psychology approaches (Holland, 1991) could be a way of developing new ideas to tackle the stigma associated with cancer as a young person, for example, or how to approach dating after cancer.

On a wider contextual level, consideration of the socio-political issues facing young people in the UK will help to formulate distress (Pilgrim, Rogers, & Bentall, 2009). Young people, particularly those from large cities, are more likely to rent and have fewer ties to the community, placing them at risk of social isolation: A recent study showed that young people aged 16-24 are more likely to be lonely than older adults in the UK (Office for National Statistics, 2018). For those working to improve young cancer survivors' emotional and psychological wellbeing, an understanding of how young people's experiences of cancer may interact with wider socio-political issues, and then how these contexts may interact with young people's experiences of relationships, seems particularly pertinent.

4.6.2.1. Talking about cancer: Clinical psychologists and other health care providers could be involved at broader systemic levels by facilitating those *around* young people to be able to have conversations about cancer. Young people frequently spoke about the additional burden and responsibility of supporting their peers and romantic partners to talk about cancer. Health professionals could be involved with supporting those working with young people (e.g. educators) to know and understand more about how talk to someone with cancer or other serious physical illness. The recent 'Time to Talk' campaign (Time to Change, 2018) aims to increase people's confidence in talking about mental health problems with peers, and the findings of this study suggest there is also a need to support people in talking openly about physical illness and its psychological effects.

Indeed, opening up opportunity for meaningful conversations about distressing or taboo subjects (such as sex, illness or death) was cited by several young people as one possible way to reduce the stress associated with cancer and relationships. Harnessing the power of social media as a platform for discussion is one potential avenue for exploration with young people. When

thinking specifically about community psychology approaches, the 'Death Café' would be one successful model to draw on for guidance.

The first Death Café was founded by Jon Underwood in London, and aimed to 'increase awareness of death, with a view to helping people make the most of their (finite) lives'. (<http://deathcafe.com/>). Interested members join a discussion group held in a local home or café, where they have the opportunity to think and talk freely about death in a non-stigmatising environment. Without an agenda or themes for discussion, the content of the session is organically created by the people attending, and there are no leaders to guide or influence what is said or how people might find it useful. The Death Café model has spread, and is now replicated and adapted across a number of different cities across the world, including being adapted for younger age groups.

In line with a community psychology approach, one initial suggestion would be for young peoples' cancer charities (e.g. TCT or Trekstock) could provide some organisational structure for young people to meet together. The remit of professionals would be to provide some light structural support, whilst facilitating young people's belief that they are in a best position to generate ideas about how to reduce the stigma around cancer with their peers. It would be important to ensure that the young people themselves took the lead and their ideas were followed through by them (Afuape & Hughes, 2016).

4.6.2.2. Challenging Dominant Discourses (e.g. The 'Body Ideal'): We know that body image problems can impact negatively on romantic relationships (Carpentier & Fortenberry, 2010), and perhaps particularly for females (Zuchetti et al. 2017). In recent years, powerful societal discourses about what constitutes the 'body ideal' are being perpetuated in ever increasing media platforms with the advent of the digital age. With this in mind, clinical psychologists and other health professionals could provide support at a broader level by thinking about how societal discourses around 'ideal bodies' can be challenged. Historically, the 'ill body' has been viewed as asexual, and the 'cancerous body' is at risk of stigma and shame (Sontag, 1978; Wendell, 2013; Wierciński, 2015). The idea of a sexually active ill person challenges dominant ideas about who is 'entitled' to sex and love (Pangman & Seguire, 2000).

Clinical psychologists may usefully support the emergence of new and varied stories available to people with impaired or ill bodies through collective narrative practice (Denborough, 2008). In recent years there have been attempts to challenge dominant narratives and extend the range of stories available about people with impaired bodies (e.g. PR campaign for London Paralympics). Although some of these approaches have been heavily critiqued (Crow, 2015), it represents an interest in the area and hopefully an opening move towards finding new ways to challenge entrenched and dominant discourses about illness and disability which pervade our worldview. Again, community psychology approaches which harness the collective power of young people themselves may be the most appropriate way to move forward, and inspiration may be drawn from the literature on AIDS and HIV (Parker & Aggleton, 2003).

4.6.3. Future Research

Future research around romantic and sexual relationships would involve more participants recruited via a range of healthcare providers, and would control for variables such as cancer type, years beyond diagnosis and relationship status at cancer diagnosis.

Specifically, this study lends support to previous studies which find that romantic relationships can be protective for young people during their cancer experience and suggests that relationship 'post-traumatic growth' is possible. One way young people achieved this was through reflection on their experience, and so future research might usefully explore the possibility of interventions which facilitate this reflective process in some way.

The findings of this study and others suggest that emotions can intensify within relationships during the cancer experience, including fear, worry, frustration and disappointment. For young people in this study, honest, open communication was one way of helping a relationship cope with the adaptations required by the cancer experience. Future research might usefully investigate this and other potential ways that young people are able to facilitate stronger relationships, perhaps via a prospective study which follows young people as they navigate the years following their cancer diagnosis. Other possible avenues for research include exploration of ways in which clinicians can support couples who are

finding this difficult, for example by comparing individual psychological therapy with other approaches.

Young people often spoke about issues regarding the 'perception' of partners, and therefore more research which details the views of partners (e.g. Friedus, 2017) would be advised, either alone or as part of a couple. It would also be interesting to find out from healthcare professionals about what support they would find most useful to be able to optimally support the young people in their care with their relationships.

4.7. Critical Evaluation

All research must be evaluated according to how usefully and meaningfully it answers the questions which first motivated it, and there are a number of frameworks available to aid this process (Stiles, 1993; Elliott, Fischer & Rennie, 1999). This study will be evaluated using Spencer and Ritchie's (2012) model, drawing on its principles of contribution, credibility, rigour and reflexivity.

4.7.1. Contribution

Contribution is concerned with how relevant the research is to theory, policy and practice (Spencer & Ritchie, 2012). Adopting a critical realist epistemological position and using thematic analysis, this study has widened understandings of how young people in their 20s experience romantic and sexual relationships in the context of cancer. The current body of literature does not include a UK sample, and there are no studies exploring differences and similarities between male and female young people, or between single young people and those in more 'committed' relationships. Furthermore, there are no studies which focus solely on young people in their 20s. Naturally, the epistemological assumptions behind the qualitative methodology dictate that the scope of the findings is relatively small. It is important to recognise that the knowledge gained is specific to the individuals who took part, each of whom is located in a specific time and cultural context. However, by addressing these above deficits in the literature, the findings may have relevance to young people with cancer or a cancer history, and the wide range of people supporting them.

4.7.2. Credibility

Credibility relates to how plausible the research claims are (Spencer & Ritchie, 2012). In an effort to demonstrate this I have included as many relevant quotes as possible and linked the findings to existing theory, which demonstrate some commonalities between my findings and those from existing studies. Although I did not ask anyone else to analyse the data, I shared some of the raw interview data and the developing drafts of my analysis with my Director of Studies, who has conducted many qualitative studies in the area. These conversations helped me to develop the overall level of analysis further, which helped to improve the overall plausibility of the research.

4.7.3. Rigour

Spencer & Ritchie (2012) propose 'rigour' as an overall term to refer to the audibility, defensibility and reflexivity of qualitative research.

4.7.3.1. *Audibility*: To ensure audibility, Spencer & Ritchie (2012) suggest that decisions made throughout the process of the research are made as transparent as possible, by clearly documenting each stage and making the reader aware of how and why decisions were taken. I have done this by recording my methodology and each stage of the analytic process in chapter 2. In chapter 3 the findings of the analysis and their conceptual frameworks are outlined and I have included extracts of raw data (Appendix K) and mind maps (Appendix M and N) to demonstrate how these themes were developed over time.

4.7.3.2. *Defensibility*: A coherent rationale for the particular sample and methodology employed in the study is a vital part of rigorous qualitative research (Spencer & Ritchie, 2012). In chapters one and two I provided a rationale for undertaking the study and why I decided to focus on young people in 'emerging adulthood' (Arnett, 2000) rather than across the entire AYA age range. The rationale behind my particular ontological and epistemological position is also outlined.

4.7.3.3. *Reflexivity*: One of the central facets of qualitative research is the researcher's attempt to 'bracket' existing theory and their own values in order to

gain an account that is as near to the experience of the participant as possible (Elliott, Fischer, & Rennie, 1999). Whilst qualitative researchers do not claim to rid themselves of their own perspective, researchers must show their reflexive attempts to understand the impact of their own position and worldview on the analysis. Spencer & Richie (2012) also suggest that the researcher reflects on the methodological and epistemological assumptions which form the basis of the study, in order to allow greater understanding of other perspectives and the limitations of the research.

4.7.3.3.1. *Personal reflexivity*: Braun & Clarke (2013) advise that reflexivity should be interwoven throughout every stage of the research process. I am aware that my personal 'lens' will have influenced the process of creating the themes, and the final sculpted result (Lyons & Coyle, 2016). However, I tried to ensure that the voices of my participants were as clear as possible by having a dynamic awareness of how my position in the world and my values may be influential at each stage. As I collected the data, I named my automatic assumptions prior to each interview in my reflective diary and identified my emotional responses afterwards. During data analysis, I ensured that I regularly returned to the transcript and field notes to ensure I was engaging fully with participant's descriptions.

As a heterosexual woman living in a 'heteronormative' society (Warner, 1991), I am likely to have a variety of assumptions pertaining to sexuality, gender identity and gender expression which will have influenced my approach to data analysis. Working in a gender identity development service as I analysed the data supported me in critiquing and questioning these assumptions, and to identify points where young people were expressing 'gendered' norms. As someone who experienced a difficult transition when moving away from my own family of origin, I also noticed that I was particularly alert to extracts where young people had experienced trouble in this area. To prevent any particular focus on this, I ensured that I returned to the coding several times and that all extracts of the data received similar level of attention. Furthermore, I was aware of my investment in 'Western' psychological theories about development, such as separation being an important process in adolescence. Although this is possible within the flexibility of qualitative analysis (Braun & Clarke, 2013),

codes pertaining to this needed several re-readings of the extracts to ensure that I was not over interpreting what young people were saying to fit my own culturally imbued ideas of what was important.

In terms of how my own position may have influenced the participants, I am aware that my role as a relatively older female will have influenced how participants chose to answer questions. I was unprepared for how reluctant young people would be in talking about sexual functioning and sexual relationships. Interacting with this was my own inexperience in asking questions about sex, and my reluctance to embarrass or upset the young people. Hollway & Jefferson (2000) suggest that research interviewing requires therapeutic skill to balance the needs of the participant with that of the researcher. On reflection, I felt there were moments when I could have confronted my own discomfort and pushed them slightly further in order to facilitate richer discussions about their sexual lives.

This related to the general challenge of navigating the interview as a trained therapist but a new researcher. It was occasionally difficult to support people in talking about emotive subjects whilst withholding interpretation or reflection in an attempt to help them. In general, I tried to encourage the young people to be as open as possible in all areas of the interview by presenting myself as robust, non-judgemental and genuinely interested in their experiences. This certainly seemed important to the young people, several of whom commented on how important it had been to talk to someone who not 'shocked' or overly 'sympathetic'.

4.7.3.3.2. *Methodological reflexivity*: The choice of a critical realist epistemology allowed me to make sense of the data using a range of conceptual tools, with an awareness of social constructions as well as a recognition of the lived reality of people's experiences. It was hoped that this particular epistemological grounding would result in research questions and findings which had utility for young people and the health professionals supporting them. Adopting a social constructionist epistemology, however, would have allowed me to pay more attention to how language shaped the experiences of young people, including how they constructed their positions in relation to wider dominant societal ideas.

The number of participants (11) is considered acceptable by Guest, Bruce and Johnson (2005), and was broadly representative of gender and sexual orientation in the general population. I am aware, however, that the sample of participants is likely to be biased; I only recruited through the Teenage Cancer Trust, and young people who were more comfortable in talking about their experiences may have been more likely to respond to the recruitment advert. Wary of not meeting my recruitment targets, I did not distinguish between types of cancers when recruiting. However, it appeared from this study and others that cancers with the most significant effects on functioning, those with poorer prognoses and those which caused impairments in sexual functioning (e.g. Carpentier, 2011), may affect the degree of impact on young people's romantic and sexual relationships.

It is important to note that as the sample was all White, there is a need to be aware of ways in which particular people of particular cultures or ethnic heritage may experience ostensibly similar medical issues in a different manner. The ethnic homogeneity of the sample raises questions for future studies, to ensure that recruitment procedures capture more ethnically diverse populations. It is possible, for example, that different cultural expectations around sexuality and relationships in young adulthood may have contributed to the lack of participation from young people of non-White populations. Recruitment may need to be more targeted to ensure that people of all ethnic backgrounds are represented and the findings can be useful for all. It is also important to mention the absence of comment about faith and religion in the analysis. Having a religious belief system is likely to have had some impact on a young person's sexual life and the choices they make about relationships, so it may have been useful to draw on this more in the analysis.

One of the study's methodological strengths was that it focused on a smaller age range within the AYA cohort. However, there were other variables which would have been optimal to address in order to compare young people's experiences more directly. This included the length of time between diagnosis and interview, and whether young people were in relationships at diagnosis or not. Further research could also usefully focus on young people who had a

significantly reduced life expectancy (e.g. due to a relapse or secondary cancer) or those with a rare form of cancer which leads to more uncertainty in how the disease will progress, as this was also mentioned as a source of distress.

Individual interviews were chosen over focus groups due to the sensitivity of the subject matter and the need to gather rich personal experience. However, if the scope of the project allowed it may have been beneficial to also interview young people with their partners, to get a different perspective on the experience and to understand how their stories are shaped differently when in conversation with each other.

The broad research questions and more specific interview questions were discussed and approved with senior members of the Teenage Cancer Trust. However, I planned to get more guidance from young people themselves about the study design by attending a young person's conference run by the charity. Unfortunately this was not possible, but I hope that future research in to the area will involve more direct input from young people in shaping designs of future research at every stage of the process, using a more participatory methodology, such as Participatory Action Research (Kagan & Burton, 2000; Kagan, Burton & Siddiquee, 2013).

4.8. Final Reflections

The findings highlight the particular needs of young people in their early 20s, who appear to have received relatively little attention in the literature compared to younger AYAs and older adults. Romantic relationships have been clearly shown to be an area of importance to young people (Robertson et al., 2016; Robinson et al. 2014; Miedema et al. 2007; Stinson et al., 2015), and they have requested more support around the issue (Robinson et al., 2014).

After the interviews, young people reported that they had found the experience a helpful way of consolidating some of what they had learnt since their diagnosis (Appendix P), and appreciated the open, genuine interest in their experiences, given the awkwardness that sometimes ensues when 'cancer' is mentioned. Several commented on the importance of the research, offering

more information if I needed it, and many showed interest in reading the completed report.

I hope they will gain some benefit from knowing more about some of the challenges and benefits experienced by other young people with cancer, and what could be done to support them. I also hope that this research may be one way of showing my support for the young people who manage stigma associated with the disease on a daily basis, and a message of hope about the potential benefits associated with managing its psychological and emotional consequences. Whilst young people may face challenges in their romantic and sexual relationships, there is also the increased possibility of psychological growth, and greater fulfillment in their relationships in the future.

5. REFERENCES

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6. APPENDICES

6.1. Appendix A: Summary Table of Empirical Papers Reviewed

Authors	Sample	Country	Design	Conclusions
Geue et al. (2015)	99 pts (66% female) aged 15-39. 100% 'in relationship'	Germany	Quantitative Standardised questionnaires on relationship quality, sexuality and sexuality needs	76% rated romantic relationship quality as high, but 64% had less sexual intercourse (more women 72%, than men 45%), and the need for support was most with changes to sexual feelings. Satisfaction with sexuality duration of relationship and being on sick leave was associated with relationship satisfaction.
Robinson et al. (2014)	55 males and females Aged 18 and 39 at diagnosis (1-5 years since cancer diagnosis)	Canada	Qualitative: - Semi-structured interviews (45-90 minutes) - Constructivist grounded theory	Core category: Dynamic interplay between experience of cancer and intimate relationship. 4 themes found within: the mental experience of cancer, challenged sexual intimacy, the relationship response to strain (supportive or non-supportive) and adapted intimacy.
Stinson et al. (2015)	20 male and female adolescents aged 12-17, and 20 parents (average since diagnosis on average)	Canada	Qualitative: - Semi-structured Interviews (approx. 30 minutes) - Thematic analysis	Dating generally 'put on hold' until treatment completion, but a significant source of support for older adolescents. Limited opportunity to meet romantic partners due to cancer

				Both YP and parents imagined cancer would affect future relationships and sex life, but parents worried more about this Both groups worried about future fertility Both endorsed need for more support around the area of romantic relationships and sexuality.
Roberton et al. (2016)	43 pts (63% female) aged 16-26. 37% in relationship <24 months since treatment completion	Australia	Mixed Methods: - Interviews using Psychological Adjustment to Illness Scale (PAIS), average 41 minutes. - chi-squared test, Fischer's exact test and independent t-tests to determine differences between participants in relationships and single	50% reported relationship/sexual difficulties. Emotional support from romantic partners was important. Communication and sexual functioning difficulties were main sources of conflict. No demographic differences between groups.
Carpentier et al. (2011)	21 male AYA with experience of testicular cancer, aged 18-34. (3-36 months since treatment completion)	USA	Qualitative: - Semi-structured interview focused on social/relational quality of life (QOL) in survivorship (average 18 minutes) - Inductive thematic analysis	4 themes constructed from data: Embarrassment leads to delays in care-seeking; testicular cancer makes you feel different from others; being different from others makes you damaged goods; cancer disclosure is difficult.

6.2. Appendix B: Application for Ethical Approval

APPLICATION FOR RESEARCH ETHICS APPROVAL FOR RESEARCH INVOLVING HUMAN PARTICIPANTS

FOR BSc RESEARCH

FOR MSc/MA RESEARCH

FOR PROFESSIONAL DOCTORATE RESEARCH IN CLINICAL, COUNSELLING & EDUCATIONAL PSYCHOLOGY

*Students doing a Professional Doctorate in Occupational & Organisational Psychology and PhD candidates should apply for research ethics approval through the University Research Ethics Committee (UREC) and not use this form. Go to:
<http://www.uel.ac.uk/gradschool/ethics/>

If you need to apply to have ethical clearance from another Research Ethics Committee (e.g. NRES, HRA through IRIS) you DO NOT need to apply to the School of Psychology for ethical clearance also.

Please see details on www.uel.ac.uk/gradschool/ethics/external-committees. Among other things this site will tell you about UEL sponsorship

Note that you do not need NHS ethics approval if collecting data from NHS staff except where the confidentiality of NHS patients could be compromised.

Before completing this application please familiarise yourself with:

The *Code of Human Research Ethics (2014)* published by the British Psychological Society (BPS). This can be found in the Ethics folder in the Psychology Noticeboard (Moodle) and also on the BPS website
http://www.bps.org.uk/system/files/Public%20files/code_of_human_research_ethics_dec_2014_inf180_web.pdf

And please also see the UEL Code of Practice for Research Ethics (2015)
<http://www.uel.ac.uk/gradschool/ethics/>

HOW TO COMPLETE & SUBMIT THIS APPLICATION

1. Complete this application form electronically, fully and accurately.
2. Type your name in the 'student's signature' section (5.1).
3. Include copies of all necessary attachments in the **ONE DOCUMENT SAVED AS .doc** (See page 2)

4. Email your supervisor the completed application and all attachments as **ONE DOCUMENT**. INDICATE 'ETHICS SUBMISSION' IN THE SUBJECT FIELD OF THIS EMAIL so your supervisor can readily identify its content. Your supervisor will then look over your application.
5. When your application demonstrates sound ethical protocol your supervisor will type in his/her name in the 'supervisor's signature' section (5.2) and submit your application for review (psychology.ethics@uel.ac.uk). You should be copied into this email so that you know your application has been submitted. It is the responsibility of students to check this.
6. Your supervisor should let you know the outcome of your application.
Recruitment and data collection are **NOT** to commence until your ethics application has been approved, along with other research ethics approvals that may be necessary (See 4.1)

ATTACHMENTS YOU MUST ATTACH TO THIS APPLICATION

1. A copy of the invitation letter that you intend giving to potential participants.
2. A copy of the consent form that you intend giving to participants.
3. A copy of the debrief letter you intend to give participants (see 23 below)

OTHER ATTACHMENTS (AS APPROPRIATE)

- A copy of original and/or pre-existing questionnaire(s) and test(s) you intend to use.
- Example of the kinds of interview questions you intend to ask participants.
- Copies of the visual material(s) you intend showing participants.
- A copy of ethical clearance or permission from an external organisation if you need it (e.g. a charity or school or employer etc.). Permissions must be attached to this application but your ethics application can be submitted to the School of Psychology before ethical approval is obtained from another organisation if separate ethical clearance from another organisation is required (see Section 4).

Disclosure and Barring Service (DBS) certificates:

- **FOR BSc/MSc/MA STUDENTS WHOSE RESEARCH INVOLVES VULNERABLE PARTICIPANTS:** A scanned copy of a current Disclosure and Barring Service (DBS) certificate. A current certificate is one that is not older than six months. This is necessary if your research involves young people (anyone 16 years of age or under) or vulnerable adults (see Section 4 for a broad definition of this). A DBS certificate that you have obtained through an organisation you work for is acceptable as long as it is current. If you do not

have a current DBS certificate, but need one for your research, you can apply for one through the HUB and the School will pay the cost.

If you need to attach a copy of a DBS certificate to your ethics application but would like to keep it confidential please email a scanned copy of the certificate directly to Dr Mary Spiller (Chair of the School Research Ethics Committee) at m.j.spiller@uel.ac.uk

- **FOR PROFESSIONAL DOCTORATE STUDENTS WHOSE RESEARCH INVOLVES VULNERABLE PARTICIPANTS:** DBS clearance is necessary if your research involves young people (anyone under 16 years of age) or vulnerable adults (see 4.2 for a broad definition of this). The DBS check that was done, or verified, when you registered for your programme is sufficient and you will not have to apply for another in order to conduct research with vulnerable populations.

Your details

1. Your name:

Philippa Rowe

2. Your supervisor's name:

Dr Kenneth Gannon

3. Title of your programme: (e.g. BSc Psychology)

Professional Doctorate in Clinical Psychology (DClinPsy).

4. Title of your proposed research: (This can be a working title)

How does cancer in adolescence affect romantic and sexual relationship development in early adulthood?

5. Submission date for your BSc/MSc/MA research:

May 2018

6. Please tick if your application includes a copy of a DBS certificate

☐

7. Please tick if you need to submit a DBS certificate with this application but have emailed a copy to Dr Mary Spiller for confidentiality reasons (Chair of the School Research Ethics Committee) (m.j.spiller@uel.ac.uk) ☐

8. Please tick to confirm that you have read and understood the British Psychological Society's Code of Human Research Ethics (2014) and the UEL Code of Practice for Research Ethics (See links on page 1) ☒

About the research

9. The aim(s) of your research:

To develop a model that conceptualises how young people negotiate romantic and sexual relationship formation in early adulthood after experiencing cancer in adolescence.

10. Likely duration of the data collection from intended starting to finishing date:

1st April 2017 – 31st July 2017

Methods

11. Design of the research:

(Type of design, variables etc. If the research is qualitative what approach will be used?)

The study will use the qualitative methodology Grounded Theory. This will involve an initial period of consultation with the Teenage Cancer Trust which will help inform research questions.

Semi-structured interviews will be conducted with young adults known to the Teenage Cancer Trust, asking questions about their experience of romantic and/or sexual relationships.

As Grounded Theory is an iterative methodology, research questions will evolve following analysis of each interview, and interview questions will be amended accordingly. Interviews will last approximately 45-60 minutes.

12. The sample/participants:

(Proposed number of participants, method of recruitment, specific characteristics of the sample such as age range, gender and ethnicity - whatever is relevant to your research)

Participants will be approximately 5 females and 5 males aged between 18 and 29 who have been diagnosed with cancer in adolescence and who have received treatment. There are no exclusion criteria relating to ethnicity or type of cancer.

Potential participants will be recruited from the Teenage Cancer Trust's database of approximately 500 young people, who have all consented to being contacted further by the Trust for research purposes. All young people in the database aged between 18 and 29 who have completed treatment will be sent a standard email with information and about the study and asked to respond if they want to take part. Those that respond will be contacted again with further details and an invitation to attend for an interview in a convenient location.

13. Measures, materials or equipment:

(Give details about what will be used during the course of the research. For example, equipment, a questionnaire, a particular psychological test or tests, an interview schedule or other stimuli such as visual material. See note on page 2 about attaching copies of questionnaires and tests to this application. If you are using an interview schedule for qualitative research attach example questions that you plan to ask your participants to this application)

An interview schedule will be developed for each interview, and the schedule will evolve as the analysis is developed. An audio recorder will be used to record interviews and enable transcription onto a password-protected computer. This computer will also be used to store transcripts.

14. *If you are using copyrighted/pre-validated questionnaires, tests or other stimuli that you have not written or made yourself, are these questionnaires and tests suitable for the age group of your participants?*

N/A

15. Outline the data collection procedure involved in your research:

(Describe what will be involved in data collection. For example, what will participants be asked to do, where, and for how long?)

1. Researcher to meet with the Deputy Director of Services at the Teenage Cancer Trust headquarters, to gather ideas for development of initial interview schedules. Conversation will be recorded in field notes.
2. Drawing on field notes, initial interview schedules, participatory email and information sheets will be finalised.
3. Researcher will contact potential participants via email giving details of the project and offering them the opportunity to respond if they would like to take part.
4. Those who respond and are interested in taking part will be sent a further information sheet and consent form to read.
5. If they agree to participate, they will be contacted via telephone to arrange a time and date for the interview.

6. Participants will be greeted at the agreed time at the location of their choice (UEL rooms or via Skype). If meeting in person, consent forms will be signed at the start of the meeting, prior to the interview commencing. If the meeting takes place via skype, consent forms will be signed and scanned via email or sent in the post prior to the date of the interview. Interviews will last for approximately 45-60 minutes.
7. Interviews will continue until no new concepts are emerging from the data. This is likely to be after 6-12 interviews have taken place.
8. Interviews will be audio-recorded and the researcher will undertake the process of transcription and analysis within three months.
9. On completion of each interview, research questions will be re-visited and interview schedules changed as necessary.

Ethical considerations

Please describe how each of the ethical considerations below will be addressed:

16. Fully informing participants about the research (and parents/guardians if necessary): *Would the participant information letter be written in a style appropriate for children and young people, if necessary?*

An information sheet will be given to all potential participants to read prior to the start of the interviews and will also be summarised verbally. Care will be taken to develop information sheets that are clear, simple and free of jargon. Participants will be given the opportunity before the interview commences to ask any questions about the research or how their data will be used if they decide to participate.

17. Obtaining fully informed consent from participants (and from parents/guardians if necessary): *Would the consent form be written in a style appropriate for children and young people, if necessary? Do you need a consent form for both young people and their parents/guardians?*

A consent form will be given and explained to all potential participants to sign prior to the start of the interviews. The form will be written in a way that is appropriate for young adults.

18. Engaging in deception, if relevant: *(What will participants be told about the nature of the research? The amount of any information withheld and the delay in disclosing the withheld information should be kept to an absolute minimum.)*

There is no deception involved in the study. Participants will be told the nature and purpose of the research when they are invited to participate and prior to their interview.

19. Right of withdrawal:

(In this section, and in your participant invitation letter, make it clear to participants that 'withdrawal' will involve deciding not to participate in your research and the opportunity to have the data they have supplied destroyed on request. This can be up to a specified time, i.e. not after you have begun your analysis. Speak to your supervisor if necessary.)

Participants will be told prior to the interview that they are free to withdraw at any time without any disadvantage to them and without being obliged to give any reason.

This will be made clear to participants on the information sheet and consent form. Participants will be reminded that if they wish any audio-recordings and interview transcripts will be destroyed. However due to the iterative nature of Grounded Theory analysis, the researcher may need to make broad reference to themes generated from a participant's interview even if they have withdrawn from the study. This will only be if changes made to the research questions, interview schedules and development of analysis need to be explained and justified. It will be made clear to participants that no specific details or quotes will be referred to if they choose to withdraw their data.

20. Anonymity & confidentiality: (Please answer the following questions)

20.1. Will the data be gathered anonymously?

(i.e. this is where you will not know the names and contact details of your participants? In qualitative research, data is usually not collected anonymously because you will know the names and contact details of your participants)

NO

21. If NO what steps will be taken to ensure confidentiality and protect the identity of participants?

(How will the names and contact details of participants be stored and who will have access? Will real names and identifying references be omitted from the reporting of data and transcripts etc? What will happen to the data after the study is over? Usually names and contact details will be destroyed after data collection but if there is a possibility of you developing your research (for publication, for example) you may not want to destroy all data at the end of the study. If not destroying your data at the end of the study, what will be kept, how, and for how long? Make this clear in this section and in your participant invitation letter also.)

Information about participants and content of interviews will be kept confidential, and this confidentiality will only be broken if the researcher has serious concerns about any person's safety. The researcher will make every attempt to talk to the young person about this before breaking confidentiality.

Anonymity will be ensured by altering any names or identifying features in transcripts, thesis extracts or resulting publications. It will be made clear that as the

final research will be shared within the Teenage Cancer Trust, there is a small possibility that contributions might be identifiable by readers from within the organisation, but the possibility will be minimised by carefully selecting quotes. Transcripts will be securely stored, and the researcher will transcribe all interviews. Only the researcher, supervisors and examiners will have access to transcripts, and this will be made clear to participants before they consent.

22. Protection of participants:

(Are there any potential hazards to participants or any risk of accident or injury to them? What is the nature of these hazards or risks? How will the safety and well-being of participants be ensured? What contact details of an appropriate support organisation or agency will be made available to participants in your debrief sheet, particularly if the research is of a sensitive nature or potentially distressing?)

N.B: If you have serious concerns about the safety of a participant, or others, during the course of your research see your supervisor before breaching confidentiality.

Interview schedules will be designed with participant's well-being in mind. However there is the potential that participants could become distressed when talking about their experience of relationships. If the researcher suspects that participants are becoming distressed at any point in the interview, the interview will be paused and the participant asked what they would like to do. They will be reminded of their right to pause the interview, to re-schedule or to withdraw completely. At the end of every interview participants will be given a debrief sheet containing contact details for further support with any of the issues raised during the interview.

23. Protection of the researcher:

(Will you be knowingly exposed to any health and safety risks? If equipment is being used is there any risk of accident or injury to you? If interviewing participants in their homes will a third party be told of place and time and when you have left a participant's house?)

There are no identified risks to the researcher. Interviews will be conducted on UEL premises or via Skype. The researcher will not be going to participants' homes. The researcher will inform the clinical supervisor and the Teenage Cancer Trust when interviews are taking place.

24. Debriefing participants:

(Will participants be informed about the true nature of the research if they are not told beforehand? Will participants be given time at the end of the data collection task to ask you questions or raise concerns? Will they be re-assured about what will happen to their data? Please attach to this application your debrief sheet thanking participants for their participation, reminding them about what will happen to their data, and that includes the name and contact details of an appropriate support organisation for participants to contact should they experience any distress or concern as a result of participating in your research.)

Participants will be given the opportunity at the end of the interview to ask any

questions and reminded of their right to withdraw from the study, including contact details for the researcher if they want to raise any concerns following the interview. They will be reminded of organisations they can contact if they experience any distress after taking part in the study.

25. Will participants be paid?

YES

If YES how much will participants be paid and in what form (e.g. cash or vouchers?) Why is payment being made and why this amount?

Potential participants will be offered a £10 amazon voucher as recognition for their time and participation.

26. Other:

(Is there anything else the reviewer of this application needs to know to make a properly informed assessment?)

4. Other permissions and ethical clearances

27. Is permission required from an external institution/organisation (e.g. a school, charity, local authority)?

YES

If your project involves children at a school(s) or participants who are accessed through a charity or another organisation, you must obtain, and attach, the written permission of that institution or charity or organisation. Should you wish to observe people at their place of work, you will need to seek the permission of their employer. If you wish to have colleagues at your place of employment as participants you must also obtain, and attach, permission from the employer.

If YES please give the name and address of the institution/organisation:

Teenage Cancer Trust
93 Newman Street,
London,
W1T 3EZ

Contact: XXX Deputy Director of Services

Please attach a copy of the permission. A copy of an email from the institution/organisation is acceptable.

In some cases you may be required to have formal ethical clearance from another institution or organisation.

28. Is ethical clearance required from any other ethics committee?

NO

If YES please give the name and address of the organisation:

Has such ethical clearance been obtained yet?

N/A

If NO why not?

If YES, please attach a scanned copy of the ethical approval letter. A copy of an email from the organisation is acceptable.

PLEASE NOTE: Ethical approval from the School of Psychology can be gained before approval from another research ethics committee is obtained. However, recruitment and data collection are NOT to commence until your research has been approved by the School and other ethics committees as may be necessary.

29. Will your research involve working with children or vulnerable adults?*

NO

If YES have you obtained and attached a DBS certificate?

If your research involves young people under 16 years of age and young people of limited competence will parental/guardian consent be obtained.

N/A

If NO please give reasons. (Note that parental consent is always required for participants who are 16 years of age and younger)

* You are required to have DBS clearance if your participant group involves (1) children and young people who are 16 years of age or under, and (2) 'vulnerable' people aged 16 and over with psychiatric illnesses, people who receive domestic care, elderly people (particularly those in nursing homes), people in palliative care, and people living in institutions and sheltered accommodation, for example. Vulnerable people are understood to be persons who are not necessarily able to freely consent to participating in your research, or who may find it difficult to withhold consent. If in doubt about the extent of the vulnerability of your intended participant group, speak to your

supervisor. Methods that maximise the understanding and ability of vulnerable people to give consent should be used whenever possible. For more information about ethical research involving children see www.uel.ac.uk/gradschool/ethics/involving-children/

30. Will you be collecting data overseas?

NO

This includes collecting data/conducting fieldwork while you are away from the UK on holiday or visiting your home country.

* If YES in what country or countries will you be collecting data?

Please note that ALL students wanting to collect data while overseas (even when going home or away on holiday) MUST have their travel approved by the Pro-Vice Chancellor International (not the School of Psychology) BEFORE travelling overseas.

<http://www.uel.ac.uk/gradschool/ethics/fieldwork/>

IN MANY CASES WHERE STUDENTS ARE WANTING TO COLLECT DATA OTHER THAN IN THE UK (EVEN IF LIVING ABROAD), USING ONLINE SURVEYS AND DOING INTERVIEWS VIA SKYPE, FOR EXAMPLE, WOULD COUNTER THE NEED TO HAVE PERMISSION TO TRAVEL

5. Signatures

TYPED NAMES ARE ACCEPTED AS SIGNATURES

Declaration by student:

I confirm that I have discussed the ethics and feasibility of this research proposal with my supervisor.

Student's name: PHILIPPA ROWE

Student's number: u1525560

Date: 16/2/17

Declaration by supervisor:

I confirm that, in my opinion, the proposed study constitutes a suitable test of the research question and is both feasible and ethical.

Supervisor's name: DR KENNETH GANNON Date: 16/12/17

6.3. Appendix C: Ethical Approval

School of Psychology Research Ethics Committee

NOTICE OF ETHICS REVIEW DECISION

For research involving human participants
BSc/MSc/MA/Professional Doctorates

REVIEWER: Dr Lucia Berdondini

SUPERVISOR: Dr Kenneth Gannon

COURSE: Professional Doctorate in Clinical Psychology

STUDENT: Philippa Rowe

TITLE OF PROPOSED STUDY: How does cancer in adolescence affect romantic and sexual relationship development in early adulthood?

DECISION OPTIONS:

1. **APPROVED:** Ethics approval for the above named research study has been granted from the date of approval (see end of this notice) to the date it is submitted for assessment/examination.
2. **APPROVED, BUT MINOR AMENDMENTS ARE REQUIRED BEFORE THE RESEARCH COMMENCES** (see Minor Amendments box below): In this circumstance, re-submission of an ethics application is not required but the student must confirm with their supervisor that all minor amendments have been made before the research commences. Students are to do this by filling in the confirmation box below when all amendments have been attended to and emailing a copy of this decision notice to her/his supervisor for their records. The supervisor will then forward the student's confirmation to the School for its records.
3. **NOT APPROVED, MAJOR AMENDMENTS AND RE-SUBMISSION REQUIRED** (see Major Amendments box below): In this circumstance, a revised ethics application must be submitted and approved before any research takes place. The revised application will be reviewed by the same reviewer. If in doubt, students should ask their supervisor for support in revising their ethics application.

DECISION ON THE ABOVE-NAMED PROPOSED RESEARCH STUDY (Please indicate the decision according to one of the 3 options above)

APPROVED

Minor amendments required (*for reviewer*):

--

Major amendments required (*for reviewer*):

ASSESSMENT OF RISK TO RESEARCHER *(for reviewer)*

If the proposed research could expose the researcher to any of kind of emotional, physical or health and safety hazard? Please rate the degree of risk:

<input type="checkbox"/>	HIGH
<input type="checkbox"/>	MEDIUM
<input checked="" type="checkbox"/>	LOW

Reviewer comments in relation to researcher risk (if any): N/A

Reviewer *(Typed name to act as signature):* Lucia Berdondini

Date: 24/02/17

This reviewer has assessed the ethics application for the named research study on behalf of the School of Psychology Research Ethics Committee

Confirmation of making the above minor amendments *(for students):*

I have noted and made all the required minor amendments, as stated above, before starting my research and collecting data.

Student's name *(Typed name to act as signature):*

Student number:

Date:

(Please submit a copy of this decision letter to your supervisor with this box completed, if minor amendments to your ethics application are required)

PLEASE NOTE:

*For the researcher and participants involved in the above named study to be covered by UEL's insurance and indemnity policy, prior ethics approval from the School of Psychology (acting on behalf of the UEL Research Ethics Committee), and confirmation from students where minor amendments were required, must be obtained before any research takes place.

*For the researcher and participants involved in the above named study to be covered by UEL's insurance and indemnity policy, travel approval from UEL (not the School of Psychology) must be gained if a researcher intends to travel overseas to collect data, even if this involves the researcher travelling to his/her home country to conduct the research. Application details can be found here: <http://www.uel.ac.uk/gradschool/ethics/fieldwork/>

6.4. Appendix D: Email from the Teenage Cancer Trust Confirming Support for the Study

Dear Philippa

I can confirm that Teenage Cancer Trust would be happy to support your study and will ensure that by following our governance around working with young people that any activity you undertake follow best practice and adhere to any relevant legislation.

Our support will include working together to facilitate the best method of data collection with young people as to get the best for your study whilst maintaining the most appropriate environment for the young people involved.

Your point of contact within the charity will be XXX XXX – Deputy Director of Services.

All the best

XXX XXX

Head of Support

Teenage Cancer Trust

MAIN: XXX

MOBILE: XXX

93 NEWMAN ST, LONDON, W1T 3EZ

www.teenagecancertrust.org

[Like us on Facebook](#)

[Follow us on Twitter](#)

6.5. Appendix E: Examples of Post-Interview Email Sent to Participants

Dear X,

Thank you again for coming to UEL and taking part in the interview on Thursday, it was great meeting you.

If you have any worries, thoughts or questions about what we talked about, please don't hesitate to get in touch. As I mentioned briefly at the end, here are details for Trekstock, which may be of interest.

<https://www.trekstock.com> Trekstock is a national youth cancer charity providing tailored physical, emotional and practical support to young people (16-39). Along with CLIC Sergeant, they're currently running a programme called Renew, a free 12 week programme where you are matched with a personal trainer to optimise your physical fitness. Also check out 'Trekstock Talks', where there's a recent talk about sex and relationships.

I will be in touch again around this time next year to give you a summary of the findings, and you should receive another email shortly with your Amazon voucher.

In the meantime, all the best with everything in the future.

Philippa

Philippa Rowe
Trainee Clinical Psychologist
University of East London

6.6. Appendix F: Recruitment Flyer

CANCER AND RELATIONSHIPS

- Were you diagnosed with cancer as a teenager?
- Are you now aged between 18 and 29?

If so, we would like to hear from you.

We want to understand more about how people experience romantic relationships after they've had cancer. You don't need to have ever had or currently be in a relationship to take part.

What would I have to do?

One interview in person or by phone, lasting between 1 and 2 hours. The interview would be with a trainee clinical psychologist.

What would I have to talk about?

Questions will be about your experiences of cancer and about how you have experienced relationships. E.g. When did you first become aware of wanting a relationship beyond friendship? Could you tell me about that?

VERY IMPORTANT! We won't talk about anything you don't want to and you can stop the interview at any time.



£20 Amazon voucher for taking part

If you are interested and want to know more, please contact:

Philippa Rowe

u1525560@uel.ac.uk



6.7. APPENDIX G: Information Sheet for Potential Participants



Information sheet for potential participants

This information is designed to help you decide if you want to take part in this research study, which is part of my Professional Doctorate in Clinical Psychology degree at the University of East London.

Research title:

How do young people who have had cancer experience relationships?

What is the aim of the research?

The aim of this research is to understand more about how having cancer as a young person affects your relationships with friends, family, and/or romantic partners.

Young cancer survivors recently told researchers that developing romantic relationships is one of their biggest concerns, but we don't know enough about how young people experience this. This research aims to find out more directly from young people themselves about what it's like.

How will the findings be shared?

The finished research will be in the form of an academic thesis. Later on, this might be summarised into an article that is submitted for publication in a journal for psychologists. Hopefully this will help young people and the services that support them to understand more about the issues involved so that they can offer the best possible support. It will also be very important to share a summary of the findings with other young cancer survivors, so that people don't feel alone and the issues continue to be talked about and addressed.

What will I have to do?

The research involves me interviewing young people individually who have experienced cancer, and each interview will take 1-2 hours. The questions will depend on what each person wants to talk about in their interview but will generally

be about your experiences of cancer and about how you have experienced relationships. E.g. When did you first become aware of wanting a relationship beyond friendship? Could you tell me what that was like for you?

There are no risks or dangers involved in taking part, although it is possible you could get upset if you were talking about something you found emotionally difficult. If this happens we can take a break or stop the interview altogether. I will also be giving you details of further support that you can access.

Where will the interviews take place?

Interviews will take place in a quiet, private room at the at the University of East London or via Skype. We can decide what is best and discuss the refund of travel costs when we arrange the details of the interview.

Is it private?

Each interview will be recorded on a digital recorder so I can remember what we talked about. Only I will listen to the recording and I will type it up into a transcript. Any names that are mentioned, including yours, and anything that you say that would mean someone could identify you will be changed in the typed version. This typed transcript may be read by my supervisor at the University of East London, and the examiners who test me when I hand the research in to be marked. No one else will be able to read the transcript. The audio file and transcript will be saved on a computer that is password protected.

After the examination, I will delete the audio recordings. The written transcript will be kept as a computer file for three years and might be used to write the research up into an article to be published in a psychology journal.

It's important that you know that there is one situation when I would need to tell someone else what we had talked about. If you told me something that made me think someone was at risk of harm, then I would need to tell someone else. But if this happened, I would try to let you know that I was going to tell someone else before I did.

Please remember!

If you want to change the time of your interview, decide to take a break in the middle or finish it at another time, that is fine. You are free to pull out at any time, even after you have finished your interview, and you don't have to give a reason. If you do pull out, it won't be a problem for the study.

In this research, the answers given in one interview might change the questions I ask the next person. As a result of this, if you pull out of the study after your interview, I might need to mention a theme or an issue that was raised by you in your interview. This might be if I need to make clear when I am writing up the research why I asked other people certain questions, or if the examiners ask me why I made certain decisions. If this happened, I would only say something very general about your interview and I would not use your exact words.

Please feel free to ask me any questions at any time. If you are happy to go ahead you will be asked to sign a consent form before your interview. Please keep this information sheet for reference.

If you have any questions or concerns about how the study has been conducted, please contact the study's supervisor: Dr Kenneth Gannon, School of Psychology, University of East London, Water Lane, London E15 4LZ. (Tel: 020 8223 4576, Email address: K.N.Gannon@uel.ac.uk). Alternatively you can contact the Chair of the School of Psychology Research Ethics Sub-committee: Dr Mary Spiller, School of Psychology, University of East London, Water Lane, London E15 4LZ. (Tel: 020 8223 4493. Email address: M.J.Spiller@uel.ac.uk).

6.8. Appendix H: Consent Form



Participant consent form

I have read the information sheet relating to this research study and have been given a copy to keep. What the research is about and why it is being done has been explained to me, and I have had the chance to discuss the details and ask questions about this information. I understand what is going to happen and what I am being asked to do.

I understand that my involvement in this study, and the things I say in the interview, will remain strictly confidential. Only the researcher will have access to information that could identify me. It has been explained to me what will happen once the research study has been completed.

I am happy to agree to participate in the study. Having agreed to do this, I know that I can pull out of the study at any time, without needing to give a reason. I also understand that if I do pull out after my interview, the content of the interview will be taken out and not be used in the study any further.

Participant's Name (BLOCK CAPITALS)

.....

Participant's Signature.....

Date:.....

Researcher's Name (BLOCK CAPITALS)

.....

Researcher's Signature

Date:

6.9. Appendix I: Interview Schedule

Introductions and engagement:

- Check they have read information sheet and signed consent form.
- Remind the participant that there are no right or wrong answers, and that that they can pause the interview or withdraw completely at any time.
- Explain that I will make a note of anything that I want to come back to while they are talking.
- Agree approximate length of interview (1-2 hours).

Preliminary questions:

1. It would help me if you could give me a sense of your early diagnosis? What do you remember about this?
2. And it would also help me to understand your situation a bit more if you could tell me a bit about your family background?

Guidance for interview questions:

1. Can you tell me about your experience of having cancer?
2. What or who helped with this experience?
3. How did having cancer affect your relationships with others? (e.g.family and friends?)
4. Did having cancer affect how you wanted to live your life as a young person?
5. When did you start to become aware of wanting a relationship with someone beyond just friendship?
6. How did you experience this?
7. Do you think your experience of romantic relationships was different from people you know who didn't have cancer? (and if so, how?)

Prompts: What happened then? Can you tell me a bit more about that? What do you mean? How did you experience that? How does that make you feel? What do you think about that? Can you give me an example? How might that have been? How was that for you? What did you make of that?

[Turn off the recorder]

Debriefing:

How do you feel about the conversation we've just had? Is there anything that bothered you about the interview? Is there anything that you'd like me to leave out of the transcript? Do you have any questions for me about what we have discussed or the study I'm doing?

- Email providing contact details of relevant support will be sent in next 48 hours
- Email address will be provided and they can contact me if they have any further questions or would like any further support with any of the issues raised in the interview.
- They are entitled to a summary copy of the findings which will be forwarded if required. This will be kept separate from all other data.

Field notes:

Social/organisational characteristics of the setting?

Participant characteristics (physical appearance and behaviour during interview)?

Personal perceptions of the person?

Any notable events during the interview?

6.10. Appendix J: Transcription Key

(...) Indicates that words have been omitted to shorten quote

[] Indicates when an explanatory comment has been added to the text

.. Represents a brief pause

... Represents an extended pause

6.11. Appendix K: Example of Transcripts with Notes

And, so a more general question really... how did your experience of cancer affect you – do you think?

Errm... I think... Well, I think, honestly what I've been thinking... recently, because it feels now like it's sort of like... well obviously... you've always got a risk of relapse but it kind of feels like... for now, like, closed book. Errm. And looking back at it... do think that it - it sounds ridiculous but I do think it's been something that's been very good for me (really). Errm... because... I dunno... I feel like... up until that point... definitely I was sort of... going through the motions a lot more in terms of my degree... and I dunno like sort of... just sort of relationships with people and stuff it was kind of like... I dunno... if that makes sense. (Yeah...) Where as now... I dunno... I think... I feel like I think a lot more... about what I'm doing. Errm... and what I want to do... errm (laughs slightly) I sound very vague... (No... No... it's difficult to clarify isn't it) Yeah! And I kind of - I dunno. Hmm. I dunno what I'm trying to say (laughs slightly)

Philippa Rowe
'It sounds ridiculous but' – acknowledgement that people 'expect' cancer to have been an overwhelmingly bad experience

Philippa Rowe
From current position, cancer experience has been 'good' for him overall

Philippa Rowe
Prior to cancer, he was 'going through the motions' in work/relationships.

Philippa Rowe
PROCESS – hesitant speech, lots of checking back, finding it difficult to verbalise his own experiences

Can you give me an example of something that you've been thinking about a lot more...or...or what you want to do?

So...I kind of...I certainly...I enjoy...I'm enjoying medicine...a lot more. And whether that's because I've had...been on the receiving end...I feel like...just...I communicate with patients...like talking to patients and stuff is like so much easier....because you see...You see lots of...because obviously I'm the year above now...everyone that's in my clinical groups...you see people talking to patients and they're so like - shaky and robotic...I just find it quite funny...I dunno, it's just a lot easier to sit and have a chat with a patient and sort of...like...enjoy what you are doing...just like chatting to people...rather than just stressing about what you're doing. Cos they might like ask much more like specific clinical questions but I feel like I get more out of it because I can just have a chat with them. And still get to the same result without being a robot. If that makes sense. So I definitely enjoy medicine a lot more. Cos there's stages where you wonder - I would wonder whether it was what I actually wanted to do. Because in the first three years you're not seeing patients. You're not really doing anything significant. Not that I'm significant now - like! (laughs briefly) It's just so much more enjoyable and it kind of occurred to me that that is what I wanted to do. Errm.

Philipa Rowe
Enjoying his career a lot more. Communicating with people is much easier, and he is able to enjoy the moment more, rather than worrying about it.

Philippa Rowe
Had previously been questioning whether career choice had been right or not?

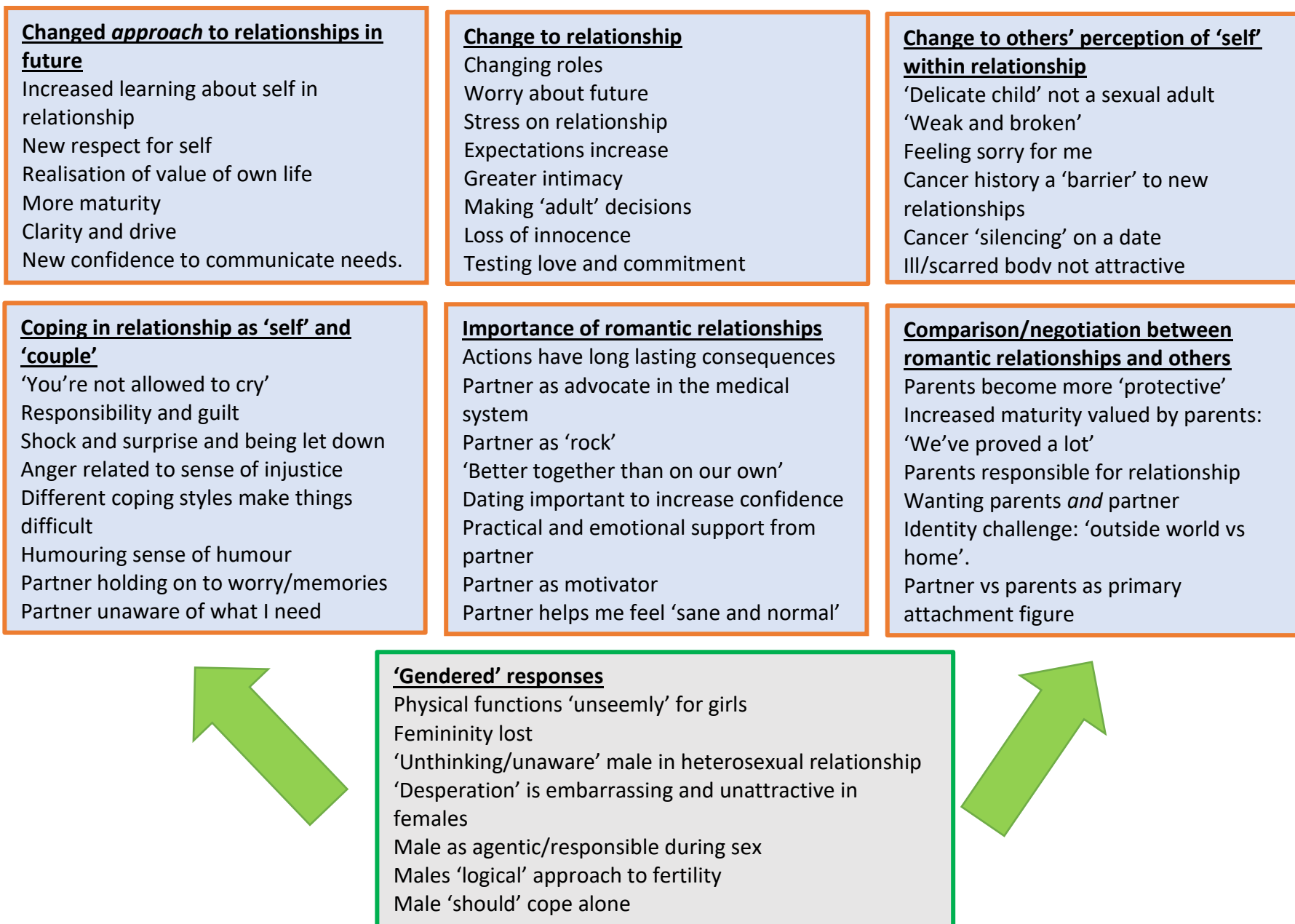
It's made it more meaningful...

Yeah! Absolutely. Errm...and yeah I dunno I—hmm...I think overall it's been a positive experience...so...so in...when was it...was it before...must have been like October time...soon after I was - re-diagnosed this year (mmm). I was getting myself quite frustrated because...last year was quite, because the treatment was quite tolerable and everything was like fairly symptom free. Errm. And I was able to see my mates regularly and everything was fine. I think everyone sort of...all my close friends at uni...sort of got the impression that it wasn't really that much of a big deal. Which was absolutely fine at that stage but then...so one thing to throw in the mix as well...before...so July last year I was diagnosed with a second cancer...I should've mentioned that earlier...

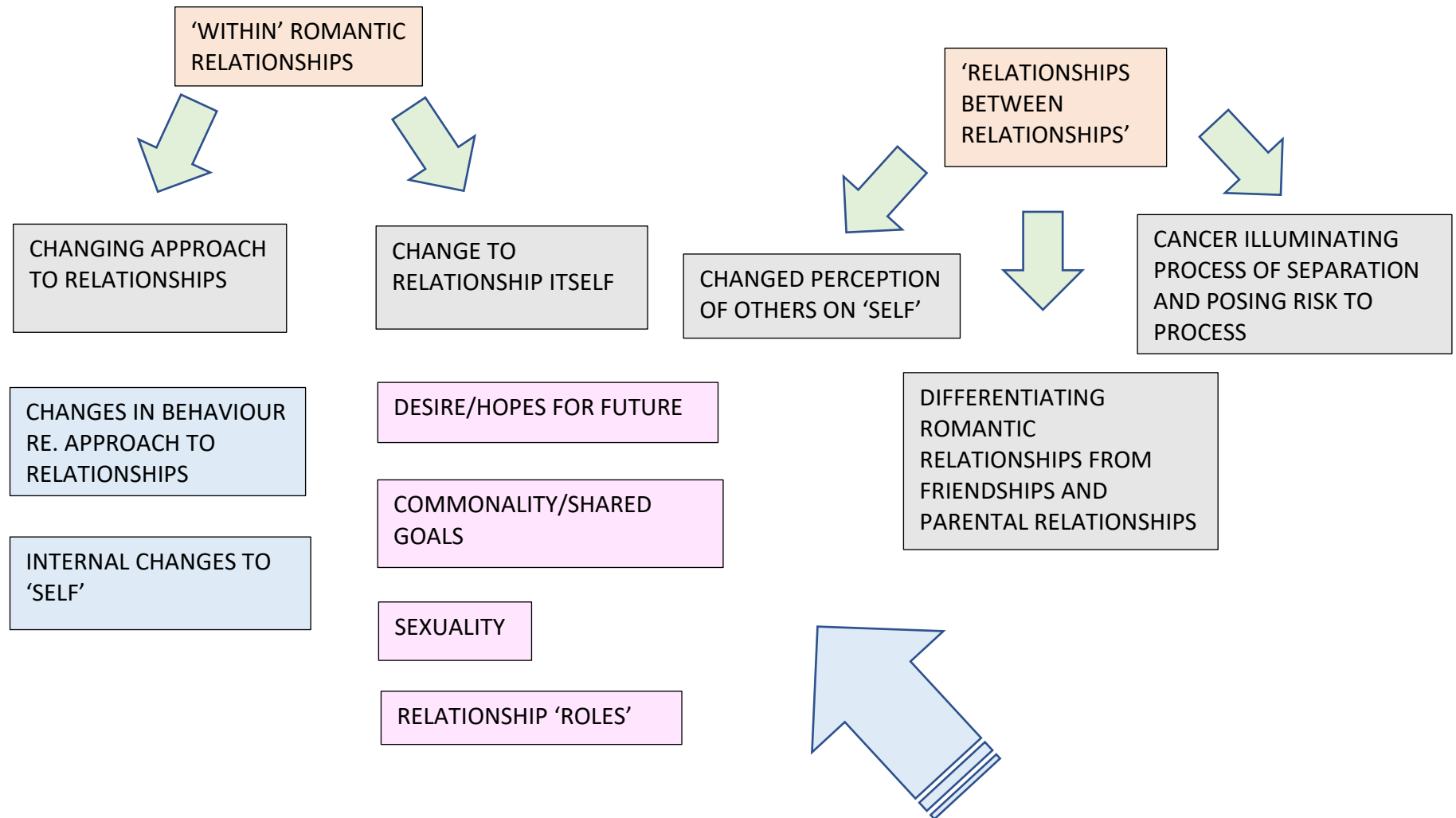
Philippa Rowe
Personal responsibility for frustration: "I was getting myself."

Philippa Rowe
Others getting the impression that the cancer 'wasn't much of a big deal'

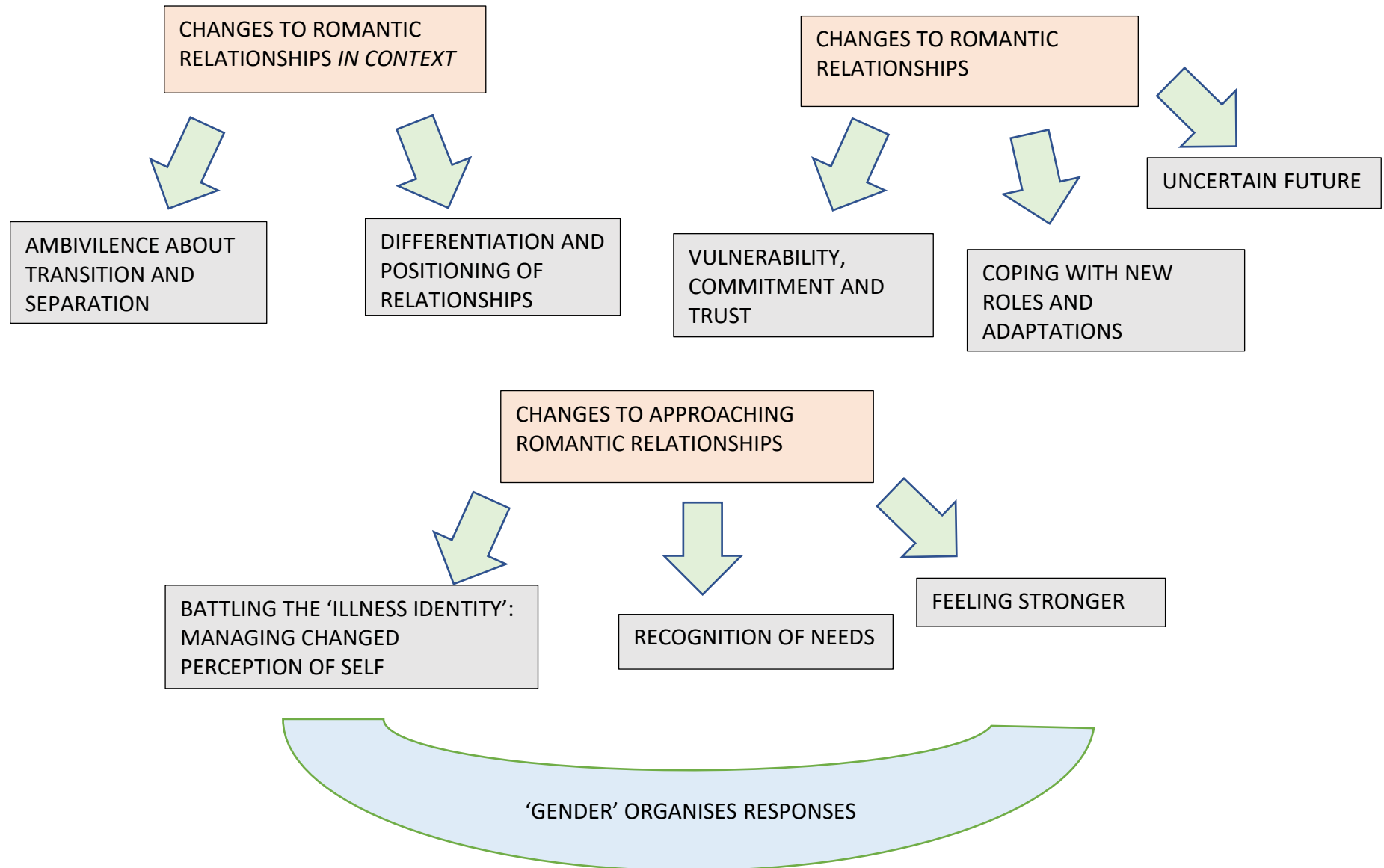
6.12. Appendix L: Initial Code Categorisation (With Example Codes)



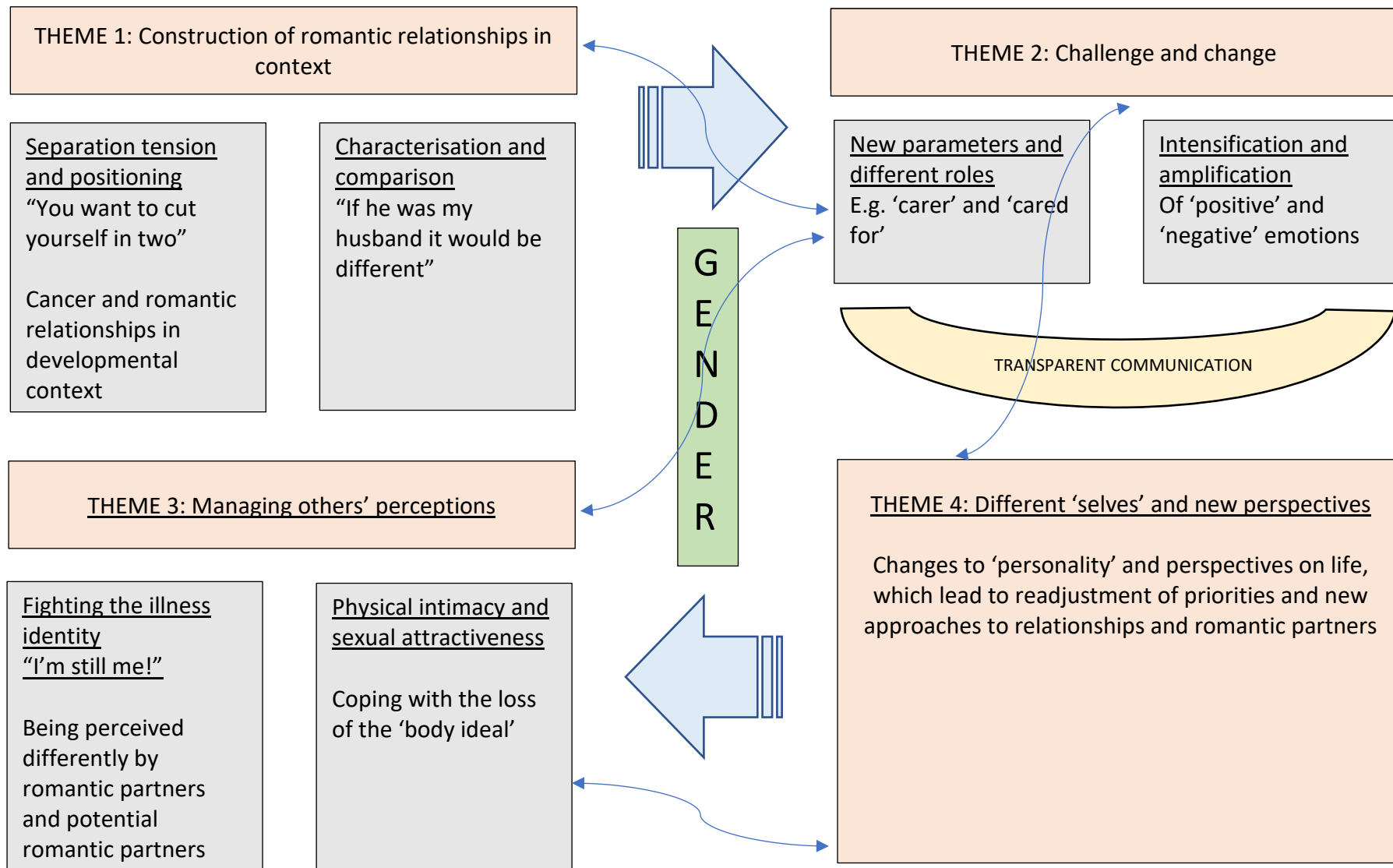
6.13. Appendix M: Intermediate Mind Map 1



6.14. Appendix N: Intermediate Mind Map 2



6.15. Appendix O: Diagrammatic Map of Themes and Subthemes



6.16. Appendix P: Feedback on Interview Process

Several of the participants mentioned that the interviews had been an interesting and useful experience, enabling them to think about and make sense of issues that they had not previously had the opportunity to do. Some felt that the openness of the discussion had been particularly useful. The following quotes are a selection of those given verbally within and after the interview.

“It’s nice to talk about it sometimes in more depth (...)it’s nice to talk to someone..that like..that you don’t know about it..it’s quite nice..’cause then..whenever you’re talking to someone that you know..you then..kind of thinking ‘oh – what can’t I say to this person...or what shouldn’t I say to this person?’..Being able to discuss it.. completely is quite nice”.

“I’ve never really thought about it, I’m enjoying this actually.. thanks for letting me do this! I never really thought about it”.

“Really good. I was looking forward to it. Um..a) because...it’s important.. it validates the value of the experience on some level...I was interested in what narrative would come out? ‘Cause..I thought about it quite a lot when...whilst being sick but since...since the summer I’ve tried to sort of get new experiences and new memories rather than...not..moping about..as in there’s only a certain level to which you can process any thoughts at any given time because it will take further development of me to look at things differently. So it was interesting to see how I was...I would tell the story after the summer...whereas in 3 years it will be different as well.

“Thank you...it’s been a very interesting experience for me”

6.17. Appendix Q: Extract from Reflective Diary

15/6/17 – Interviews 1 and 2 (Sam and Becky)

Feelings before I started?

I was nervous. Hoping Skype and audio recording would work! Wondering about how to achieve a balance between sticking to the interview questions and going with where the interviewee takes me.

During the interview

I was engrossed and looked at the time very rarely. I had to concentrate a lot to pick up certain themes and to try and remember that I was not there to 'treat' but just to observe, so had to stop myself from interpreting what they said. Occasionally I became nervous (stumbled over the word 'bone marrow transplant') and sometimes felt there were long pauses as I struggled to think of what question to ask next! I felt nervous that I would say the wrong thing and show my ignorance about cancer (especially in front of medical student!) and also felt nervous about getting into discussions about sex, although I hoped I hid this well. I felt I generally got the right balance between sitting with distressing moments (e.g. worries about not getting an erection and then asking for the next question) without needing to 'fix' it and maintaining a sense of empathy and rapport during the interview. It felt very important but challenging to get the balance right! My biggest mistakes were long winded questions (several at a time), and I will try and remember this for the next interview.

Afterwards

Feeling very relieved it has gone okay, particularly the face to face interview, where the conversation 'flowed' more. I worried about not pushing Becky a little more (e.g. links between experience of cancer and bipolar/depression) but actually felt that her conceptual understanding of these disorders may have prevented her from making any links, and a direct question about it might have been unethical or leading. I felt moved by both participants at different times during the interview, but noticed the urge to support Becky particularly strongly, perhaps because of her particularly challenging situation. At times I thought that Sam may have felt more uncomfortable talking to me about sex (not necessarily relationships) and wondered how my voice and what I looked like might have affected both participants. With Sam the face to face nature of the interview made it easier to establish a rapport. Chatting before the interview as we made our way to the room, we found we had a love of cycling in common. I wonder how this common experience and the rapport affected the interview.

Overall first impressions and learning points

I found both participants to be quite different, and each had quite different experiences of relationships in context of cancer. I feel I've learnt quite a lot already about how gentler, very open questions can elicit the rich information you want - at one point I asked a rather blunt question about masculinity and it didn't go anywhere, so I will learn from my mistakes for the next ones!

There may be a few common themes from both. Interestingly, both mentioned how their cancers had made them more attractive to potential partners, although neither

seemed too pleased by this. Both participants talked about psychological/emotional growth, although in different ways, which may have been reflective of the different ages at which they were diagnosed (the first at 14 and the second at 21). Sam felt strongly that he wouldn't have been mature enough to be in his current (very happy) relationship if he had not experienced cancer. With both there was a sense of wanting to let me know that they had struggled but were finding their way out of it. Although Becky was most obviously distressed by some of her experience, there was also a sense of vulnerability from Sam, but this seemed somewhat disguised.